DOCUMENT RESUME

ED 271 912 EC 190 220

AUTHOR	Edgerton, Robert; Ottina, Jean
TITLE	A Twenty-Five Year Follow-Up Study of Persons Labeled Mentally Retarded.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	Mar 86
GRANT	G008430026
NOTE	203p.; Some charts contain small, broken type.
PUB TYPE	Reports - Research/Technical (143)
EDRS PRICE	MF01/PC09 Plus Postage.
DESCRIPTORS	*Adjustment (to Environment); *Child Rearing; Ethnography; Followup Studies; Individual Characteristics; *Mental Retardation; *Parent Attitudes; Prediction; *Success

ABSTRACT

In a follow-up of 407 mentally retarded children first studied in 1959, the study examined contributing influences of parental attitude and child-rearing practices as well as the larger society's socializing practices. Original demographic and attitudinal data were used to predict the functional adjustment of 70 members of the original cohort. Those adults found (on parents' ratings) to be doing much better or much worse than predicted were examined ethnographically. An attempt was made to detect factors that might account for successful or unsuccessful life adjustment. Among observations made of this group were (1) that the mothers were more accurate in assessing and predicting their children's life adjustment than were social agency or institutional personnel; (2) that problems associated with sexuality and physical and mental abuse were quite prominent; and (3) that cultural expectations relating to growth and development as envisioned in mainstream society were in conflict with these persons' individual patterns. The study points out the roles that mothers play in the lives of their retarded children and stresses their need for specific directions for helping those children at each stage in their lives. A six-page list of references is included. Nearly half the document is comparised of 13 appendices that include: Leichman's 1959 Interview Scales, including those pertaining to home environment; sample questions from the Progress Assessment Chart of Social and Personal Development; sample items from the Parental Attitude Research Instrument (PARI) and the PARI scoring sheet; the 1959 and 1983 standard scores on the 23 scales of the PARI; and seven life histories. (CL)

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ED271912

A TWENTY-FIVE YEAR FOLLOW-UP STUDY

OF PERSONS LABELED MENTALLY RETARDED

Department of Education
Grant Number G00-84-30026
(Program Number 84 023)

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March 1986

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Abstract

A FOLLOW-UP STUDY OF PERSONS LABELED MENTALLY RETARDED

Parental attitudes and child-rearing practices and the socializing practices of the larger society influence the life adjustment of the mentally retarded individual. This study attempted to identify some of these contributing influences with a follow-up of a sample of 407 mentally retarded children first studied in 1959. The original demographic and attitudinal data were used to predict the present functional adjustment of 70 members of the original cohort who were located. The parents of these retarded adults assessed their children's present functioning, and those who were found to be doing much better or much worse than predicted from the earlier data were identified for further intensive study.

An in-depth ethnographic study of the most extreme outliers was conducted, with comparisons being made to similar data on persons whose present functioning was accurately predicted from earlier data. These persons were observed in a wide variety of settings. Life histories were established from information collected in 1959 and on events that have occurred in the lives of these people during the interval since the earlier 1959 study. This information included the intervening experiences with family, school, community, and work. An attempt was made to detect factors that might account for successful or unsuccessful life adjustment.

The results of this study included nine observations:

1. The mothers of these persons were more accurate in assessing their children than outside social agencies and institutional

personnel. They were also accurate in predicting the future life adjustment of their children.

2. The objective measures collected in 1959 and 1983 did not predict the detailed pattern of adjustment of these persons because of lack of validity of the predictor scores, precluding an adequate assessment of causal life history influences of outlier status.
3. Problems relating to sexuality and physical and mental abuse were quite prominent in this group.
4. Retardation was a family problem and could not be dissected into isolable elements affecting individual members.
5. Participants in the study who had depended on social services for support had less stable life histories than those who were less involved with such agencies.
6. Cultural expectations relating to growth and development as envisioned in mainstream society were in conflict with these persons' individual patterns.
7. These persons were not different in kind from a so-called "normal" population. Differences were a matter of degree.
8. Some form of work was important to the satisfaction of these persons. Their perceptions of quality of life reflected their parents' attitudes.
9. The mothers wanted specific information about what to do to help their children at each stage of life, beginning at birth.

Such findings have implications for educational interventions. The findings may also inform those who are involved in parental guidance, teacher preparation, and research on special populations.

PURPOSE

A number of investigators have speculated on the relationship between adult adjustment of mentally retarded individuals and the early child-rearing practices and attitudes of their parents (Saenger, 1957; Zigler and Harter, 1969; Begab and Richardson, 1975; Edgerton, 1984). For example, Zetlin and Turner (1984) have distinguished between parents who encouraged normal activities and risk taking, set realistic goals for their children and pushed until a reasonable degree of self-sufficiency was reached, and parents who had difficulty adapting to their handicapped child and the associated stigma, or tended to be overprotective and overregulating and restrictive of their child. The children of these two styles of parenting grow up with different adjustment patterns. The retarded children of the accepting parents tended to grow up accepting their limitations and seeking out normative achievements that confirm their success as adults. The children of rejecting parents were less likely to strive for normative accomplishments and became either embroiled in a wasteful struggle to reconcile their handicap with their desire for normalcy, or deny their limitations by striving for routinization of their lives and continuation of the status quo which permits them to continue the self-deception of accomplishment and self-maintenance.

It is also apparent that socialization practices of the larger society, beyond the home and family, play an important role in altering the future adjustment of the mentally retarded adult. Zetlin and Turner found differences in adjustment between younger and older adult cohorts. They report a correlation of .76 between years of independent living and

self-acceptance. Further work is needed to uncover the connections between early parental attitude and child-rearing practices, the subsequent life history events that socialize these persons, and their adult adjustment patterns.

A rich, untapped source of baseline data on attitudes and child-rearing practices of parents of retarded children was collected twenty-five years ago by Leichman (1962), who interviewed 407 mothers and administered the Parental Attitude Research Instrument (PARI) (Shaefer and Bell, 1958). His interviews were patterned after Sears and Maccoby's seminal work Patterns of Child Rearing (1957) and Bandura and Walters' work with adolescents (1959). The children ranged in age between three and nineteen then, so are between twenty-eight and forty-four now. During the past two years, 140 of Leichman's original cohort of parents have been located. They have been interviewed and asked to take the PARI again. In 1983, a subsample of 70 mothers was administered an Americanized version of the Progress Assessment Chart of Social and Personal Development, Form 2 (P-A-C 2) (Gunzburg, 1976).

Some interesting results have been found from these interviews. School seems to be an especially important socializing factor. The personality of the special education teacher was perceived by the mothers of these retarded adults to affect not only the child's progress in school, but also his later adjustment. Some parents have said that their child dropped out of school because of the special education teacher's personality, while many mothers attributed their child's success as an adult to a special teacher who was patient and caring or helped their child find a job.

Patterns of parenting also emerge from the new interview material. Some parents said they know what they were supposed to have done but don't know how they could have changed their own behavior, while others outlined their ideas of dealing with a handicapped child and told what they did. My initial results support Zetlin and Turner's (1984) argument that there is a need to understand how to help parents of mentally retarded children in their parenting. Parents of the mentally retarded often are still involved with their children after they become adults, so their parenting patterns continue to affect their child's adult adjustment.

Parents complained about the social service delivery systems. Services are provided for the obviously handicapped persons but not for more mildly retarded persons who function fairly well, yet cannot be fully independent and still need help. "He has just slipped through the cracks," said one mother. "They have been studying all these years, and they haven't been able to help my son. What he needs is a job with a boss that understands him," replied the father of a man who could perform more than the routine tasks of a workshop but sits in a board and care home watching TV. Richardson (Begab and Richardson, 1975) concluded from his research that professionals as well as parents need more understanding of the life course of people with differing degrees of mental subnormality.

In my investigation, most parents were concerned about what would happen to their children when they were gone. One parent whose child had been moved from a well-run institutional setting to an abusive board and care home said, "I thought my child was all taken care of until this

normalization. Now, I know that I can't count on anything." The parent finally found a good board and care home, but worried that the person running it would die before her son did.

These 1983 interviews have generated many hypotheses that can only be investigated through a close examination of the retarded person's life in process. I was especially interested in outlier cases where these retarded adults have achieved unexpected adjustment levels. Perhaps the best way to examine a phenomenon is to study the exceptions. The subjects I have selected for in-depth study are exceptions: those functioning worse or better than might be predicted from the data obtained from parents. I compared these outliers with those who are functioning as might be predicted from their level of handicap and home environment.

Thus, the purpose of this research was to conduct a 25-year follow-up study on a selected sample of retarded adults whose parents were originally interviewed in 1959. This study was based on an analysis of 1959 and 1983 interview material and intensive observations of seven individuals over a two-year period.

The study has five major purposes:

1. Determine the adequacy of the Americanized P-A-C 2 to assess the adaptive behavior of moderate and mildly retarded persons and those with borderline intelligence living in the community.
2. Determine if a prediction equation using IQ, handicaps, and home environment factors can accurately predict adult adjustment of mentally retarded individuals.

3. Learn what critical life events affected the adult adjustment of these mentally retarded individuals.
4. Compare perceptions of quality of life of the retarded subjects as reported by parents, teachers, and social service workers with self-reports by the retarded themselves.
5. Discover some clues about how to guide parents and teachers of retarded children.

The enthusiasm that professionals and social service delivery systems in the southern California area have shown as they have assisted me in the search for Leichman's original cohort and the quality of advice they have given on measures and procedures used in the study provided early evidence of the worth of this project. Other studies have not had such a large amount of information about the original cohort (Saenger, 1957; Baller, Charles, and Miller, 1966; Cobb, 1972), nor have they spanned such a long period of time. In addition, the potential of keeping in touch with the located cohort and following them into old age creates a longitudinal component that is unique.

Finally, there has been an intrinsic benefit of the study that should not be neglected: the benefit to the participants themselves. As parents and their now-grown children have been contacted, they have not only been willing to participate but have expressed hope that they can make a contribution to others who will experience what they have. They want to talk about their successes and failures, and their participation seemed therapeutic for them.

RESEARCH METHODS

Preparation and Selection of Sample

The individuals chosen for the follow-up study were drawn from those children and their parents who were located from the 1958-59 study, entitled Parental Attitudes in Rearing Mentally Retarded Children (Leichman, 1962), sponsored by the California State Department of Education with funds from the United States Office of Education, Department of Health, Education and Welfare. Leichman's sample was composed of 407 mothers who had children labeled mentally retarded by a school psychologist or by a physician. There were 205 educably mentally retarded (EMR) children and 202 severely mentally retarded (SMR) children living in three counties of southern California.

Preparation

Before the study could begin, a number of preparatory steps were necessary. The data base from Leichman's 1959 study included detailed demographic data, tape recorded interviews, IBM cards containing coded demographic and interview data scored on 255 scales and tables (Appendix A), and results of the Parental Attitude Research Instrument (PARI) completed by the mothers at the time of the interview. There was a case folder for each child in the study. These materials were checked for completeness and usability; the tapes were played and catalogued; a printout was made of the IBM cards; and a new code book was prepared. The scoring of the interviews was checked for accuracy by listening to a tape and scoring the 255 scales and tables and comparing these scores to the printout. Eighty-nine percent of the scales were virtually

identical to the 1959 ratings as shown on the printout. We were satisfied that the old data were in usable form.

Next, enough members of the 1959 cohort had to be located to make a follow-up study worthwhile. When 150 had been located, with leads to 50 more, it was determined that enough would be available for a follow-up of the 1959 study.

Because the follow-up study uses an ethnographic approach partially relying on verbal reports from retarded respondents, a sample of 70 persons was drawn only from the EMR group of the original cohort. The located sample was representative of the larger EMR sample, as shown on Table 1, which compares the located sample to the original EMR cohort.

Since IQ and adaptive behavior measures are used to place children in school and determine eligibility for special services, I wanted to assess the now-grown adult's functioning with an adaptive behavior assessment. The AAMD Adaptive Behavior Scale (Nihira, Foster, Shellhaas and Leland, 1975) was considered, but it had been normed on an institutionalized population, and the cohort for this study was living in the community. Although some work had been done with it in the community, those norms were not yet available. In a personal communication, Zetlin[1] told me that it did not discriminate at the higher levels well enough and suggested the Progress Assessment Chart (P-A-C) (Gunzburg, 1976) or the Community Living Skills Quick Screening Test and the Vocational Training Quick Screening Test (Schalock and Gadwood, 1980, 1981). I examined these instruments, as well as the

[1] One of the authors of the chapter entitled "The measurement of adaptive behavior" in Handbook of Mental Deficiency, Psychological Theory and Research, edited by N.R. Ellis, New Jersey, Lawrence Erlbsum Associates, Publishers, 1979.

TABLE 1

Comparison of Located Sample to the Original EMR Sample

	% of Original Sample	% of Located Sample
Sex		
Male	55	61
Female	45	39
IQ		
Borderline intelligence (70-88)	49	55
Mild retardation (55-69)	43	29
Moderate retardation (44-54)	9	16
Ages		
6-8 now 30-32	8	10
9-17 now 33-41	86	77
18-19 now 42-43	6	13
Socio-Economic Status		
Upper	16	16
Middle	36	39
Lower	48	45

Vineland Social Maturity Scale (Doll, 1965), since a shortened form of the Vineland is still used by many school districts. A further consultation was held with Nihira,[2] and he also recommended the P-A-C because of its discrimination at the upper levels of functioning. The P-A-C 2 was finally chosen to administer to mothers of the now-grown children.

The P-A-C manual was studied carefully by an associate and myself and we each administered the P-A-C 2 to two mothers of mentally retarded adults who were not in our cohort. The mothers critiqued the test and the administrators' performances. We compared differences in our scoring and discussed the instrument as a potential tool for the study. The instrument had two difficulties. It was written in British English and each question was too long, creating the possibility for a different interpretation with each administration. Some questions demanded lengthy explanations. We rewrote the P-A-C in more concrete, standard American English. It was readministered to two other mothers of mentally retarded individuals and the administrations were tape recorded. We listened to the recordings item by item to identify items that were understood differently from the intended meaning as stated in the P-A-C manual. Such items were revised and this revised P-A-C 2 was administered to two more mothers. A final draft was then prepared and administered to two experts who both worked in the field of mental retardation and who were also mothers of mentally retarded adults. They were asked to judge the final draft, give their understanding of the

[2] Personal communication, March 1983. Nihira is one of the authors of the AAMD Adaptive Behavior Scale and an author of the chapter entitled "The measurement of adaptive behavior" in Handbook of Mental Deficiency, Psychological Theory and Research.

questions, and make any suggestions they wished. These sessions were tape recorded and a final version of the Americanized P-A-C 2 was written, with a few changes suggested by these judges.

When the P-A-C 2 revision was completed, the Exceptional Chidlren's Foundation (ECF) and the Regional Centers in southern California were asked to help contact, from our sample, the parents whom they serviced. The ECF and Regional Center parents and the parents located through the phone book and voter registration microfiche were sent letters of introduction signed by the director of the 1959 study, Dr. Nathan Leichman. A packet was then sent to each mother, including an explanation of the project, an information sheet to update socio-economic information, and a PARI.

Each of the seventy located mothers was interviewed for one and a half to two hours on the phone, and was asked to respond to the P-A-C 2. The interview inquired about the retarded adults' present residence, marital status, job history, job training, school history, and handicaps; parents' perception of what helped and hindered their child; etiology of retardation; and whatever the parents wanted to say. The mother was allowed to talk about what she wished before any questions were asked, so those ideas that were uppermost in her mind were expressed.

Next, a level of handicap had to be determined for each EMR subject. Using the statistical reporting section of the AAMD Classification in Mental Retardation (1977), handicaps of the retarded individuals reported in the 1983 parent interviews and 1959 demographic information were classified by ambulation, vision, hearing, speech,

arm-hand use, spasticity, and seizures. Appearance and psychiatric impairment were added to these categories. The AAMD manual's rating system was used to rate each subject on each handicap category (Appendix B). To reduce the number of categories, a factor analysis using the P-A-C 2 functioning data was performed. Those handicaps loading heavily on each factor were multiplied by their loading factors, and each individual's handicap score was computed by adding their weighted scores from each factor.

The next step was to derive a measure of the retarded individual's childhood home environment. Current literature suggests at least seven areas that ought to be considered in a home environment: amount of warmth toward child, lack of punitiveness on the part of the parents, harmonious family, encouragement of learning, acceptance of child's retardation by parents, parent receiving support from a parent group, and a stimulating home environment (Azam, 1973; Jehan and Qusari, 1981; Nihiria, Mink and Meyers, 1981; Poznanski, 1973; Zaman, 1976; Zelin, Turner and Winik, 1982). There are thirty scales in the 1959 interview that pertain to these areas (Appendix C). Using the sample of 407, the scales were factor analyzed and those scales loading heavily on each factor were multiplied by their factor score and added together to obtain a single, combined home environment score for each individual in the subsample. The three factors that composed the home environment score were labeled family harmony and father's affection, acceptance of the child's retardation by the mother, and lack of punitiveness. The participants' home environment factor scores are in Appendix D.

Selection of the Sample

Finally, using the P-A-C 2 score as a dependent variable, and IQ, the derived handicap score, and the derived home environment score as independent predictor variables, a multiple regression analysis was performed. Regression coefficients were obtained for each variable and their values were employed in the prediction equation to identify outlier subjects who were more than two standard deviations above or below the regression line; those were the subjects who were doing much worse than might be predicted or who were doing much better than might be predicted. These subjects--two above and two below the regression line--were selected for continued intensive study. Of the many subjects who were on or close to the regression line, two who were geographically accessible were chosen for further intensive study. In addition, one person who had his master's degree and was working in his chosen profession was studied in depth.

Intensive Study of Subjects Selected from the Regression Analysis

Research Design

The overall design for the study was a single subject research design (Edgerton & Langness, 1978). However, a follow-up evaluative survey was used to identify the outlier/exceptions and to compare each extreme using a static group comparison approach.

Conceptual Framework

The study addressed three dimensions. The first dimension was the environmental settings to which the mentally retarded person must adjust: home, school, work place, and community. The second dimension included the characteristics that the retarded individual brings to the environment or setting: abilities, handicaps, prior learning, personality, and emotions. The third dimension included the sources of influence that may operate in each setting: role models, benefactors, opportunities, and consequences.

Within this framework, the ethnographic-like methods used were participant observation and life history.

Research Approach

Participant Observation and Life History Procedures. The participant-observer accompanied the mentally retarded person in his everyday activities, joined him for special occasions such as birthdays, took him to places he needed to go, and helped him with problems in his life. In addition to understanding each subject's typical day, week, or month, the participant-observer studied each person over time in multiple settings. She/he also introduced each person to some new settings to gain information on their learning, problem solving, and adaptive strategies. The participant-observer attempted to see and understand the world as it is seen and understood by the subjects.

Detailed field notes were taken and, as feasible, conversations were tape recorded. A sample from preliminary notes taken on one of the individuals chosen for the ethnography are as follows:

I had called at 12:30 and arrived at 2:10. S was on the front lawn with a cardboard box containing her cat and kittens. She was waiting for me. I had mentioned that I wanted to see the new kittens. There were five. S described how she helped the mother cat give birth by gently easing the kittens out. She cupped her hands and demonstrated how she did it. S remembered the last time she had watched kittens being born and how her mother had helped them. S grimaced, "There were a lot of afterbirths. I'm glad we're not cats."

Our visit had not been planned ahead of time. S's hair was straight and brushed down; it is pretty thin. She had no make-up on and she had a lot of dark hairs growing on her face. She wore blue slacks and a flowered blouse. She was clean but not tidy.

The life history approach used in this project included "critical event analysis" similar to the "event analysis" reported by Edgerton and Langness (1978). An event that the mentally retarded person mentioned as being critical to his development or adjustment was examined from multiple points of view using longitudinal data. The mother's recollections in the parent follow-up interview and comments taken from the 1959 interview were compared to the mentally retarded person's perspective. Others who were involved in the event also were sought and interviewed. In addition, the participant-observer looked for evidence of the effects of the "critical event" in the behavior of the mentally retarded adult.

For example, one of the persons being studied had postponed our meetings several times because of a cold, sore throat, flu, or stomach cramps. Health seems to be an issue with her. Her elementary school teacher was interviewed and asked how her health affected her schooling. The teacher replied

That's kind of the way it was when I wanted so desperately to say to Mrs. X [the participant's mother], "She needs to be here. Don't let her get by with this." I would go as strong as I could, but then Mrs. X would say, "Well, what do <u>you</u> know about it?"

The investigator studied each person in his various roles as family member, student, client of the delivery system, employee, and spouse. This effort attempted to create life portraits that were more complete than descriptive profiles derived from cross sectional survey methods. Each retarded adult was seen over a period of at least eighteen months. The names given to the participants to maintain confidentiality were the following:

	Men	Women
Outliers above regression line	Steve	Anna
Participants on regression line	Bobby	Lori
Outliers below regression line	Donald	Susan
Participant with Master's degree	Rod	

Persons Who Were Not Accessible. The men who were to participate in the study were protected by their parents more than were the women. In 1983, the parents had been contacted in order to assess their child's functioning on the Progress Assessment Chart. During the next phase of the project, the parents of the outliers and two cases from the regression line were asked to help us make contact with their sons or daughters. The subjects to be contacted were two men and two women who lay two standard deviations from the regression line and a man and woman from the regression line. When the parents of the men were approached, they were emphatic that they did not want their sons contacted. They had been cooperative, giving us names of teachers and counselors who could give us information about their sons, but they did not want their sons disturbed.

The mother of the man who was above the regression line, Steve, told us that he was tired because he had two jobs and worked a half day

on Saturdays. She said that he spent Sundays with his wife and friends and therefore was too busy to participate. She said that she had had a long, hard struggle keeping him in school and keeping him happy. "I just want to put all of that behind me now, and Steve would agree." The teacher that she put us in contact with said that Steve was not identified as being retarded now, and his mother undoubtedly wanted to protect him from any association with retardation that he had had in the past.

The mother of the man who was below the regression line, Donald, said that she had had a cancer operation recently and got easily upset. She said, "Donald is peaceful and relaxed for the first itme; I don't want him to get excited." She didn't want him questioned because she said he liked attention but when he got it, that was the end of his good work. "I may be overprotective, but our lives are peaceful now and I don't want that to change. I have changed my whole way of thinking. All people are different and children keep changing. What you learn about Donald won't help others as they grow up. An expert told me to put him away when he was six months old, and I didn't follow that. I'm glad I didn't," she concluded. However, his elementary school teacher and one of his social service counselors was asked about his falling apart when he got attention and they both had not observed that to be true. He had recently been on a television news program, had led a group through the workshop at open house, and had been photographed with celebrities visiting the facility and still had continued his work in the workshop. What his mother did not say was that Donald had gotten into trouble and she and his father had been invited to a meeting to

discuss his continuing at the workshop and group home. Donald's mother did not want anything else to disturb him at that time. She had had trouble finding a place for Donald all his life.

The father of the man chosen from the regression line expressed the same contempt for the "experts" as did Donald's mother. "They have been studying all these years and haven't been able to help. It's circumstance and economics," he said. His son is in a group home and watches TV most of the time. He has a psychologist that helps him, but his father feels that he needs a job in which the employer would understand his son's inability to cope with pressure. The father did not want us to visit his son because "he needs to be on an even keel." When the mother was interviewed in 1983, she had said, "I remember going to bed at night and saying, 'God, please help me.'" Her husband says that he and his wife look back a lot now rather than forward, and she thinks of what she might have done and it's not good for her, so he did not want to participate further in the study.

In contrast to the parents of the men, the mothers of the women who were not living at home referred us to their daughters. The mother of Susan, who was living at home, said that she would like to help us all she could. Only one daughter declined to participate and that was the one chosen from the regression line. She said she was having personal problems and didn't have time just now. Her mother agreed that now would be a difficult time for her daughter. Another woman, Lori, was chosen from the regression line, and her mother gave us Lori's telephone number, telling us to ask her daughter if she would like to participate. Lori was eager to help us.

The two men who were outliers and had to remain in the study could be observed, even though neither of them was contacted. One had made a video tape that was aired on television, and the other worked in a public place. They were observed briefly to check the accuracy of the reports of teachers, social workers, counselors, and parents.

Participants Who Were Accessible. Another man on the regression line, Bobby, was chosen for comparison with the outliers, and his parents were cooperative, yet protective. Bobby lives at home, and his parents allow him freedom within strict parameters. They knew about all of our contacts with him beforehand, except once when the participant observer and Bobby went somewhere when his parents weren't home. Although a note was left for them, his mother checked with me later and expressed some concern over the visit.

Anna, the woman above the regression line, agreed to help with the study, but she didn't want it to interfere with her usual activities such as going shopping and to lunch with her friends, playing bingo, or helping other members of her family. She knew that her husbnad would object to her participation because he was such a private person, so we first made contact when she visited her sister. She never felt comfortable when I visited her in her apartment. I usually joined her in one of her activities such as playing bingo at a bingo parlor, or took her to her sister's house. We always talked either at a restaurant or in the car. She only called me once, when her husbvand left for the summer without her. She had refused to go and was confused about her own feelings, being torn between her husband and her twin sister. At first I thought that she wanted someone to talk to, but, in fact, she

wanted a ride to her sister's house. Her good friend had been on vacation and had arrived home after she called me, and they had been talking when I arrived. Even though her husband was a very closed person, she talked with me openly. Sometimes she didn't tell everything when it was to her advantage not to, but usually she was quite frank.

The woman on the regression line, Lori, and the one below it, Susan, were always glad to see me for I gave them a chance to talk about themselves and have some recreation. Their lives were not as independent, and I was able to make a contribution to them while they were helping me with the study.

One man among the group of seventy in the study, Rod, obtained a Master's degree and was asked to participate in the in-depth study. He was more than willing to do so.

Follow-up Parent Interviews. When the participant observation was nearing an end the mothers were interviewed using the follow-up interview schedule described in the instrumentation section. This interview lasted between five and nine hours, depending upon how much the parent wanted to digress, and was conducted in two or three sittings.

Participant Observers. Two participant-observers were used to take life histories and do participant observation: one man and one woman. Henshel (1972) noted that better rapport is gained with investigators of the same sex and culture as the respondent. There were three men and three women in the sample being studied. Although the participant-observers were assigned to their sample according to sex, both observers met the members of the sample. They took their field

notes independently and compared them at the time of the final data analysis. Both were present during the parent interview and filled out the post-interview scale independently. At regular intervals the participant-observers evaluated their observations to help them plan further activities that would help fill in missing information.

Instrumentation

Three instruments were used in the study: the Progress Assessment Chart of Social and Personal Development, the Parental Attitude Research Instrument, and the Follow-up Interview Schedule.

Progress Assessment Chart of Social and Personal Development

The Progress Assessment Chart of Social and Personal Development (P-A-C) (Gunzburg, 1976) has six versions for well-defined groups. Form 2 is designed for adults who are moderately or mildly retarded or who have borderline intelligence. It was standardized on a population of 144 mentally retarded persons ages 15 to 31. A 1979 study (Ryan, 1979) indicated that data from the P-A-C have near normal distribution. The total battery has an inter-rater reliability of 0.97. Gunzburg (1980) noted that although the P-A-C was not designed as a "test" for social competence, it has been used by many workers for that purpose. He added that research results on statistical reliability have been published and show the P-A-C to be a very satisfactory assessment instrument. A review of the P-A-C assumed that Gunzburg claimed a face validity for the scales in all six versions (Myers, Nihira and Zetlin, 1979). Sample questions from the revised P-A-C are in Appendix E.

Parental Attitude Research Instrument (PARI)

The PARI was developed as a comprehensive concepualization and quantification of parental attitudes toward child-rearing to serve as a research instrument for future studies. A conceptual analysis was made of items used by Mark (1953) and Shoben (1949). Items were constructed attempting to make them differentiate effectively between parents of normals and parents of maladjusted children. For example, one item is worded "'Children need some of the natural meanness taken out of them.' The apparent truism seems to give the respondent with a latent but defended attitude a feeling that it may be socially acceptable to agree" (Shaefer and Bell, 1958:348). It was found that tests composed entirely of more differentiating items left many mothers feeling that there were no items with which they could agree, and therefore some "rapport" scales that were expected to have low reliabilities and poor discrimination were included. Shaefer and Bell tried four forms of the instrument, improving its discrimination and reliability each time. Form IV (the final form), which was used in the 1959 Leichman study, consisted of 23 subscales of five items, each arranged cyclically so that the first subscale includes items 1, 24, 47, 70, and 93, etc. Reliabilities were estimated with Kuder-Richardson Formula 20 for each subscale and ranged from .34 (one of the "rapport" scales) to .77.

Shaefer and Bell (1958) stated that although predictive validity studies had not yet been done on the PARI, a review of the literature lent weight to the concurrent validity of their general approach to the study of parent-child relationships. A study done by Zuckerman and Oltean (1959) comparing results of the PARI to results from the

California F Scale, the Edwards Personal Preference Schedule, the Minnesota Multiphasic Personality Inventory, and a test of self-acceptance concluded that the results indicated some relationship between personality variables and attitudes toward child rearing and offered some evidence for the construct validity of the parental attitude factors of the PARI. Although further research is needed to support the PARI's reliablity and validity, it has been used frequently as a research instrument.

The PARI was given to the parents in the 1959 study and it was readministered in the follow-up study. Sample items from the PARI are in Appendix F.

Follow-up Interview Schedule

The interview schedule for the follow-up study included questions pertaining to all three dimensions of the framework used for this study. Those questions pertaining to settings, personal variables, and sources of influence from Leichman's 1959 interview schedule were adapted to parents of adult children.

A parent interview schedule used by Turner, Zetlin and Gallimore, of the UCLA Socio-Behavioral Group in an investigation of personal and social adjustment of retarded persons living in community settings, was consulted. It paralleled the questions selected from the 1959 interview schedule and included some objective measures of personality and home environment.

It was decided to use the Socio-Behavioral Group's interview because it had been tested and improved. Additional questions adapted from Leichman's 1959 interview schedule were inserted.

The revised interview schedule was administered to a mother of a mentally retarded adult not in the research sample and was changed to alleviate difficulties encountered. A sample of the Follow-up Interview Schedule is in Appendix H.

Data Analysis

Sources of Data

There were six sets of data to be analyzed for the persons studied: 1959 taped mothers' interviews and demographic information, notes from the 1983 parent telephone interviews, PARI responses from 1959 and 1983, notes and tapes from field observations, parent interviews conducted in 1985, and video tape interviews.

1959 Mothers' Interviews and Demographic Information. Careful notes were taken on the tapes of the 1959 mothers' interviews. These notes and the demographic information were used in the construction of the chart, entitled Appendix G, Information on Seventy Subjects Labeled Mentally Retarded. They also were used to provide examples for the general observations described in the results section and in the construction of the Life Histories (Appendix M).

1983 Parent Telephone Interviews. Information from the 1983 parent telephone interviews was also used in the construction of the chart in Appendix G. This chart enabled comparisons of the persons in the intensive study with the seventy cases of the initial cohort. Notes from the telephone interviews were examined and categories were created from the major topics suggested by the interview questions and the material volunteered by the parents. The notes from the 1983 parent interviews were typed onto computer diskettes and sorted by computer

into these major categories. An example of the sorted notes is in Appendix I. These notes also were used to provide examples for the General Observations in the results section and to construct the Life Histories.

PARI Responses from 1959 and 1983. Raw scores on the twenty-three scales of the PARI administered in 1959 and 1983 were converted to standard scores. The standard scores of the mothers of the outliers and of those on the regression line were compared to detect a pattern that would explain the outlier status (Appendix J).

The standard scores on the PARI were also compared to the home environment factor scores derived from the 1959 parent interviews to check for consistency between the written PARI responses and the oral responses. In addition, field observation notes were compared to the PARI standard scores to check for consistency of attitudes when inferred from written respones as contrasted with observed behavior.

Notes and Tapes from the Field Observations. Tapes from conversations with the participants and interviews with teachers, social workers, siblings, or other persons involved with a critical event were transcribed and, together with field notes, were typed onto diskettes. This material was also sorted into categories suggested by the material. The computer printed out this material in both chronological order for each participant and sorted by categories and participants. An example of the sorted notes is in Appendix K. These materials, all 1959 and 1983 interview material, and 1985 parent interviews were studied to find general observations that seemed true of a participant. Generalizations were identified via a process of triangulation. That is, where several

sources of information separately pointed to the same pattern, where observations were verified in multiple sources, a generalization was described that summarized the convergence among data sources. When the generalizations were listed, frequency counts were made of behavioral instances fitting each general observation. In addition, instances of affect associated with each general observation were noted to signify the importance of each to the retarded individual. The instances were listed by the paragraph and line number from the computer printout. An asterisk was put next to those instances with strong affect. An example of this process is in Appendix L.

Those general observations that had many instances or especially strong affect were ascribed to that participant. Those general observations that had few exmaples or weak affect were discarded. Then the general observations for each participant were compared to every other participant to sift out common patterns that might elicit hypotheses to explain the deviation of the outlier P-A-C 2 scores. These hypotheses were then explored in a detailed examination of field notes and all other material gathered for each participant. They were supported where possible with anecdotes and quotations from the six data sources. Counter examples were also noted and discussed.

1985 Parent Interviews. The post-interview scales for each 1985 parent interview filled out by the two participant-observers were compared. The discrepancies were discussed and resolved. Information from the post interview scales was used also in deriving the general observations. The tapes of the 1985 parent interviews were transcribed on diskettes and printed out by computer. These print-outs were

carefully analyzed for examples of the general observations. They were also used in the construction of the Life Histories.

Videotapes of Participants. Videotapes were made of four participants, parents, a participant's teacher, and a participant's therapist. The videotapes were initially planned as teaching devices utilizing the outcomes of this study. However, they proved to be an invaluable source of original data. For example, field notes indicated that even though Susan's mother had always been open about Susan's retardation, Susan didn't use the word in her conversation. During the videotape interview, Susan began to cry when she spoke of retardation, but this reaction wasn't apparent until the tape was seen. At the time of the interview, her reaction was not observed by either the interviewer or the cameraman. The videotapes were viewed several times and notes were taken. The voices on the videotapes were recorded on cassette tapes and transcribed so that they could be read as well. The new information from the videotapes was added to the Life Histories.

Outliers Compared to Similar Cases from the Cohort of Seventy

The outliers were compared to those of the seventy who had common characteristics such as same sex and similar IQ to discover factors that may have contributed to their being outliers. For example, one outlier, Susan, who was two standard deviations below the regression line was compared to other women who had about the same IQ. We looked at all the material we had on each: 1959 mothers' interviews, handicap scores, home environment scores, 1983 parent interviews, P-A-C scores and answers to each P-A-C question, and PARI results from 1959 and 1983. In this case, the major difference seemed to be the handicap scores. When

we studied the field notes pertaining to her health, we discovered that she too had health problems, but they were not the apparent ones associated with mental retardation and were not reflected in her handicap score. This is an example of the comparative type of analysis that was done. The information from this comparison was included in the detailed examination of field notes and other materials to check the hypotheses explaining the deviation of the outliers.

Method by Which the Conclusions were Drawn.

Both the outlier comparisons in the Results section and the Life Histories (Appendix M) were examined in order to find reasons for the participants' outlier status and to address the five major purposes of this study. From this examination, statements that could be made about the participants were listed, and examples of these statements taken from the Life Histories and other data sources were used to illustrate each point.

Methodological Assumptions

The mothers' assessments of the outliers on the P-A-C 2 could be checked by observation. If the outlier scores were verified, it was assumed that the scores of the entire located sample would be verified also.

A second assumption was that enough rapport could be gained with the outlier respondents so that everyday life could be observed by the participant-observer.

Limitations

The located sample of mentally retarded adults is probably not representative of the population of mentally retarded adults as a whole. At the time of the original study, SMR children represented only six percent of the retarded population in California, and yet they constituted half of the original sample. In the population as a whole, the majority of retarded children are mildly retarded; in the EMR original sample, borderline intelligence represented 49 percent, while 30 percent were mildly retarded, and 20 percent were moderately retarded. In addition, the small number of participants in the study precludes generalizing the outcomes to other mentally retarded adults.

RESULTS, CONCLUSIONS, AND IMPLICATIONS

The results are presented in five parts: Preliminary Analyses, Information on the Participants, Life Histories, Outlier Comparisons, and Conclusions. Implications for parents, school personnel, and social workers are presented in the final section.

Preliminary Analyses

Adjustment of Seventy Persons Labeled Mentally Retarded

An analysis of the data collected from the seventy interviews of parents of children who had been labeled mentally retarded twenty-five years ago found a large number adapting well to adult life in the community. Forty-six percent were living independently; seventy-seven percent were employed competitively, and forty-one percent had held their competitive jobs for five or more years. Only one was living in an institution (Appendix H).

Regression Analysis

The 39.7 percent of the variation on the P-A-C 2 scores was explained by the additive combination of the handicap score, IQ, and home environment scores. The unique contribution of each variable is shown in Table 2. For each standard deviation increase in the handicap score, there was a .415 standard deviation decrease in P-A-C 2 score. For every one standard deviation increase in IQ score, there was a .382 standard deviation increase in PAC 2 score, but for every one standard deviation increase in home environment score, there was a .201 standard deviation decrease in PAC 2 score. The handicap and IQ scores each

accounted for almost twice as much PAC 2 score variation than did home environment. There was a significant negative correlation between the self-help and employment components of the PAC 2 and the home environment score which would indicate that the higher the home environment factor scores, the lower the scores on self-help and employment.

Table 2. Proportion of P-A-C 2 Scores Explained by Each Major Predictor

For each 1 SD increase in:	Variation in PAC scores in SD's:	
	Increase	Decrease
Handicap		.415
IQ	.382	
Home environment		.201

1959 and 1983 PARI Analysis

The two mothers who refused to contact their sons for the intensive study of the participants also refused to respond to the PARI in 1983. All seven mothers of the participants responded to the PARI during the 1959 interviews (Appendix J).

There was no particular pattern of PARI responses that distinguished mothers of outliers from mothers of those on the regression line. When the PARI standard scores were compared to the 1959 parent interview factor scores, no pattern was found to explain outlier status of the participants based upon these measures.

The PARI responses seemed fairly consistent with observed behavior of the mothers. For example, both Lori's and Rod's mothers had scores almost two standard deviations from the mean on Inconsiderateness of the Husband and Marital Conflict. The participant-observers' field notes offer examples of the lack of family harmony in these homes, and both mothers eventually divorced their husbands.

Information on Participants

Table 3 contains information on those participants who were selected for intensive observation. The names assigned to the participants are fictitious for purposes of confidentiality.

Outliers

The two outliers, Steve and Anna, who were doing better than was predicted had IQ's in the moderately and the moderately to mildly retarded range. They were both in their forties. Steve had no other handicaps. The cause of his retardation was illness during infancy. His father was a mail carrier which places him in the middle socio-economic group. Steve graduated from high school and has worked competitively for twenty-five years. He lives independently with his wife of five years and has no children.

Anna, who was doing better than was predicted, had mild difficulty in arm-hand movement, was slightly spastic, and was reported to be very nervous, which prevented her from driving. She was a twin and had been injured during birth. Her father was a barber, which places him in the lower socio-economic group. She dropped out of high school and has worked competitively for no more than three months at a time. She has been married for seventeen years but has no children.

TABLE 3

Description of Participants

Information on Participants	Two SD Above Regression Line		Two SD Below Regression Line		On Regression Line		With Master's Degree
	Steve	Anna	Susan	Donald	Lori	Bobby	Rod
Etiology	Ill during infancy	Birth injury	Birth injury & ill during infancy	Developmental delay, origin unknown	Ill during childhood	Ill during infancy	Not retarded
IQ	51	44	56	53	88	73	68
Handicap Scores	None	A2,B2,C2	None	D2,A2,C4	A2,E3,C4	F3	None
Married	Yes	Yes	No	No	No	No	Yes
No. of children	None	None	None	None	None	None	2
Father's Duncan Socio-Economic Index	G	H	H	G	G	H	G
Residence as of Jan 1985	I	I	L	K	J	L	I
Education	N	M	M	M	NO	N	NO
Employment	P 25 yr	P <1 yr	R <1 yr	R	QR	P 17 yr R >1 yr	P 8 yr
Age - 1959 - 1985	18 44	16 43	9 36	13 39	13 39	17 44	6 33

A = Arm-hand
B = Spasticity
C = Psychiatric impairment
D = Vision
E = Seizures
F = Speech
G = Craftsman, clerical, small business owner
H = Laborers and service workers

I = Living independently
J = Living semi-independently
K = Board and care home
L = Parents' home
M = Did not finish high school
N = Finished high school
O = Post-secondary
P = Competitive
Q = Subsidized
R = Workshop

2 = mild
3 = moderate
4 = severe

The two outliers who were doing worse than was predicted were in the moderately to mildly and the mildly retarded range. Susan and Donald were in their late thirties. Susan had no other handicaps, but she is obsese. She was injured during birth and had an illness during infancy with a high fever and a convulsion. Her father was a lead man in a factory, which places him in the lower socio-economic group. She dropped out of high school upon the advice of a physician. She worked in a sheltered workshop for a short time during high school, but has not worked since. She lives at home with her parents, has never been married, and has no children.

Donald has mildly impaired vision, is slightly spastic, and has severe emotional problems. He is considered developmentally delayed, but the cause of his handicap is unknown. His father owns a small business, which places him in the middle socio-economic group. He dropped out of school before entering junior high. He had been working in a sheltered workshop until recently and was living in a group home affiliated with the workshop. He has never been married and has no children.

Participants on the Regression Line

Two participants who were geographically accessible, Bobby and Lori, were chosen from the regression line. They both had borderline intelligence, and both had had serious illnesses during infancy or childhood to which the doctors had attributed their slowness in learning. Bobby's mother, however, had worked with retarded babies and suspected that something was wrong when he was three weeks old before his illness. Lori has mild arm-hand impairment, seizures, and severe

psychiatric problems. She was also obsese but has since lost weight. She is in her late thirties. Her father worked in an office, which placed him in the middle socio-economic group. She finished high school and goes to junior college in a special program for the developmentally disabled. She works in a program for developmentally disabled adults called the companion program. She lives with a senior citizen and works to pay for her room. She has never been married and has no children.

Bobby's illness had paralyzed his vocal chords and he has a moderate speech impairment. He has no other handicaps. He is in his early forties. His father was a bus driver, which places him in the lower socio-economic group. He finished high school and has worked competitively for seventeen years. He had worked in a sheltered workshop for a short period of time before being competitively employed. He lives at home with his parents and has never been married and has no children.

Participant with a Master's Degree

The accomplishments of one other participant, Rod, were so unusual that he seemed worthwhile studying. He has his master's degree from a local univeristy and works in his chosen profession. His IQ was reported by a school psychologist as being in the midly retarded range when he was placed in a special class. He is not retarded, however, and has no other handicap, although he had an articulation problem when he was in school. He is in his early thirties and has worked in his profession for the past eight years. His father was a mail carrier, which places him in the middle socio-economic group. He lives with his wife and two children.

Life Histories

Life histories of Anna, Steve, Donald, Susan, Bobby, Lori, and Rod are presented from several points of view representing the sources from which the information was drawn. First, information comes from the participants themselves as revealed to the participant-observers over a two-year period. Second, detailed information about the participant's was given by their mothers in the 1959 interviews, 1983 telephone interviews, and the 1985 parent interviews. Finally, persons important to the participants such as siblings, teachers, therapists and counselors contributed information about the participants through interviews conducted over the past two years (Appendix M).

Outlier Comparisons

The general observations in this section are the results of a two-year association with the families of the participants. They represent an analysis of field notes taken during approximately two hundred hours of talking, shopping, eating, working, playing, and studying with them. In addition, they represent an analysis of all other data sources.

By a process of triangulation, these general observations were derived for each person studied. Six factors were found to be common to both sets of outliers and to those participants from the regression line: dependency, special vulnerability to stress, developmentally delayed learning, high levels of abuse, frequent problems with expressing sexuality, and perhaps as a consequence of these factors, families that were exceptionally involved with their children. These six factors will be presented in the first part of this section.

In the second part of this section, the factors that distinguish those who were doing better from those who were doing worse than predicted will be presented.

Observations Common to Outliers and Participants Selected from the Regression Line

Dependency. All participants studied were dependent on someone such as parents, siblings, benefactors, or a spouse. Their helpers either made decisions for them or intervened at significant times to help them maintain an independent lifestyle.

For example, Steve's junior high school teacher has been a benefactor to him. His teacher helped Steve get his first job and, when that business sold out, he helped Steve get a job in a hospital's food services. When Steve's employers tried to "help" him by promoting him to a more responsible job that was too stressful for Steve, his teacher again interceded, helping Steve return to his old, less stressful, job. He has held that job for fifteen years and it enables him to live independently with his wife, who also works.

Anna depends on her husband for transportation, filling out applications, and handling the household finances. She also depends on her twin sister to help her make decisions such as what to order in a restaurant, even though Anna can read the menu. When they were in school, Anna depended on her twin sister to protect her from those who stole her lunch or her money.

Bobby and Susan live at home and are dependent on their families. Both Bobby's and Susan's mothers are housewives and they perceive their jobs as taking care of the family, which includes their dependent son or

daughter. They wash Bobby's and Susan's clothes and cook their meals. Although Bobby works, he is financially dependent on his family. His parents do not want him to contribute toward the household expenses, because his money must be invested to create a resource for him when they are gone. Susan's Social Security Income (SSI), would not allow her to live independently in the comfortable style that she enjoys in her parents' home. Susan's parents consider the SSI to be her money, not part of the household income.

Lori and Donald depend on the social service system for their jobs and housing and thereby give up their right to make many decisions for themselves. Lori has two social service workers whom she depends on to mediate if she and her senior companion are not getting along. These workers have felt it necessary for her to go to therapy, and she depends on her therapist to be her advocate when she disagrees with the social service workers. She depends on many different people for advice: her companion, her companion's neighbor, her friends, her relatives, nurses from hospitals where she has stayed, and the hot lines. When she has a problem she calls all of these sources for advice, giving the impression that she could not solve a problem by herself.

Donald lives in a group home and works in a workshop, so his life is completely dependent on the system in which he exists. His parents also control him as if he were a minor. Although, legally, he could participate in this study without his parents' permission, the social workers in charge of his programs would not cooperate with the researchers without the permission of his parents. His parents' wishes are considered before his. For example, when he wanted to go to a

church service of a denomination other than his faith, his parents told his social worker that they did not want him to go, and he was denied that privilege.

The participants are dependent because there are things they have not been able to do for themselves. As a result, they are controlled by those who help them. When a balance is maintained between the needs of the participant and the needs of the family or social service, an optimum lifestyle is the result. When one person or agency is considered to the detriment of the other, the quality of the participant's life suffers.

Vulnerability to Stress. All six participants had trouble coping with stress, and what might be stressful to them might not be viewed as stressful by those around them. For example, one time, after Steve was given a more reponsible job in the hospital where he worked, he was asked to get something from a closet quickly because an emergency had arisen. He froze. When he finally got the item from the closet, he just threw it down. He didn't understand why his coworker had been short with him, for he couldn't see that pressure makes others speak sharply. The hospital planned to fire him, but before letting him go, hospital personnel talked to the teacher who had recommended him. The teacher offered the obvious solution: Steve should return to the job that he could handle. He liked the work and felt comfortable in the job; he had no need to advance. When asked to do more, he froze.

Bobby, Lori, and Susan have had similar experiences. When Bobby began his present job, he couldn't cope with being ordered to do things by the other workers, nor could he cope with their humor when it was

directed at him. He wanted to quit. His mother made a bargain with him: if he stayed for a week, she would take him to Hawaii. In the meantime, she spoke with his employer, telling her that Bobby was a good worker if he was not teased or expected to work too fast. An effort was made to take the pressure off Bobby at work, and he has now held the job for nine years. Recently, a pretty young coworker was observed pretending to run him down with the dish cart, and he laughed at the joke. He plays baseball with his coworkers and enjoys the comraderie with them. His parents saved their money and finally took him to Hawaii to complete the bargain.

Lori had workshop training in high school and, when she graduated, stayed at the same workshop. Her job was sorting and she enjoyed it, for when she achieved her quota, she helped the others achieve theirs. She did so well that she was promoted to soldering. Her instructor wasn't patient while Lori was learning the new task and yelled at her; Lori went crying to the office. They explained to her that that her instructor just had an explosive personality, but Lori couldn't deal with her so she quit the workshop. If Lori can't escape frustration, as she did when she quit the workshop, she inflicts pain on herself. She has tried to commit suicide three times and was observed to have scratched the length of her thigh when she became angry with her senior companion. She needs a large support system to help her maintain equilibrium in her job and her daily life.

Susan also enjoyed working at the Goodwill workshop. She says, "It was great working in the store, but they made me change. I was putting nuts and bolts in a box. When someone talked to me, I lost count. I

was supposed to have ten pieces, but I had too many. They bawled me out so the other workers could hear. I cried and wouldn't come out of the restroom. The other workers laughed, and someone called me a cry baby." Susan left the workshop and did not return. Susan has had similar experiences at school and at church. She dropped out of school because her teacher embarrassed her in front of the other students by implying that she was absent for no reason and denying her permission to go to the restroom. Her doctor advised her to quit rather than be continually upset. At church, she enjoyed helping in the nursery during the services until they wanted to leave her alone with the children, which was more responsibility than she could handle. The people at church would say, "Susan could be normal if someone would teach her." Susan stoped helping in the church nursery. Her mother says some parents, teachers and employers put too much pressure on handicapped children and the children have mental problems as a result because they can't stand pressure.

When Anna gets nervous, her hand shakes. She had trouble working in a coffee shop because if she were under pressure, the hand that served the coffee would shake. "When I get upset, I cry, and then I can't speak." Both her mother and her husband agree that she would be too nervous to drive a car, although she has her drivers license. In the past, her reactions to stressful situations has been extreme. One time, while changing buses in a bad part of town, she was told to take a shortcut through an alley to get to the other bus station. "I got into the alley, and then I saw two black men there....I was so scared I fell down and threw up. I got to the other bus station and got the other bus and didn't get to my mom's until 7:30."

Donald's mother says that if he feels secure he can handle a situation, but that he falls apart under stress. She did not want us to talk to him because she said that he was peaceful for the first time in his life and she did not want anything to change that.

Developmentally Delayed Learning. Both outliers and participants on the regression line reported important basic learning taking place while they were in their twenties, thirties, and forties after the normal school-age period. The assumption, reportedly made by vocational rehabilitation counselors of workshop clients, that retarded people should have learned all of their basic skills while in school appears to be antithetical to retarded persons' rates of progress in learning.

Lori says that when she was in elementary and secondary school she didn't understand what the classes were or the significance of the grades. When she was older, school had more meaning. She signed up for reading in junior college and got a "B+" in the class. She cried from happiness because she had never earned such a good grade before. She could hardly wait to tell her mom and dad, and they were very proud of her. When she wanted to learn to type, she bought a typing book and practiced on her mother's typewriter at home. She learned about money and counting change from an old math book after she was out of school. Now, at age thirty-eight, she is back in junior college taking reading and math and loving it. She also goes to a speech therapist to work on her language deficit and is learning to balance her checkbook.

Anna remarked that she was so turned off by school that nothing stuck; she has learned far more since she left school. Her father's cousin tutored her for a short while and she learned from him because

she wasn't bothered by anyone, there was no noise, and he was a "more stricter person." She has also learned to read better because her husband encourages her to sound words out as she reads the newspaper. "You can do it," he'll say. She is conscious of learning basic skills daily.

Donald's mother claims that Donald didn't get anything out of the special class he was in at school, but when he was nineteen he improved greatly when she took him to Delecato training. The Delecato method teaches basic coordination patterns, beginning with learning to crawl. The instructors taught Donald's mother how to work with him, and she worked with Donald eight hours a day for a year. He started swimming and he could concentrate. Not only did his coordination straighten out, but his basic skills improved. He could swim, bowl, play baseball, and he went from not knowing his alphabet to reading at a third grade level. His elementary school teacher remembers him as being spastic, with involuntary head and neck movements, while his present workshop counselor says that he is not spastic and has no involuntary movements.

Since Susan has been participating in this study, she has a renewed interest in learning her basic skills. While checking Susan's functioning on the Progress Assessment Chart, the participant-observer noticed that she was improving in reading skills as she read signs in the shopping mall. While her knowledge of money was being tested, she improved from question to question. Now, her brother has supplied her with a computer and educational software, and she likes working with it. She says that it doesn't tell her that she is wrong; it just tells her to try again, so she can repeat as many times as she needs to. It

doesn't make her feel bad and, at age thirty-five, she is working on a very basic reading vocabulary.

High Levels of Abuse. The mothers of all the participants complained that their children were made fun of by other children and adults because of their handicaps. However, Anna, Donald, and Lori suffered exceptional abuse, both while growing up and as adults, because of their handicaps. Others treated Anna cruelly in school, at work, and even in her own family. "School was a really miserable time for me," Anna said. Both her mother and her twin sister came to her defense, but ultimately it was the cruel treatment by her peers that caused her to drop out of school before she graduated. When she worked in a coffee shop, both the other waitresses and a customer told her to quit because they didn't like the way she talked or looked. After they were grown, two of her sisters said they hated her because her mother babied her and they had to do her share of the work. Even one of Anna's nieces asked her why she talked and looked funny and told her that she wished she were dead. When Anna talks about her life these are some of the things that are told with great emotion and are mentioned first.

When Donald went to a special school for all handicapped students, he liked school and did well. After his family moved and he was in a special class in a regular school, he didn't want to go to school any more. His teacher says that he would come in from the playground with his shirt torn and his nickel or dime taken. When his mother said that he would blow off steam at home, his teacher said, "No wonder, he was always trying to be perfect at school and never showed anger at anyone but was upset when the others got him dirty." He stayed with the teachers a lot at recess.

Lori received the most abuse; not only did her father hit too hard when she was noisy and he wanted to watch television, not only did the kids at school call her "cootie bug" and hit her in the face, but she was also abused sexually. She was molested during childhood and has been raped three times since she has grown; one of the men who raped her was her stepfather. Her therapist feels that the sexual abuse has caused severe emotional problems. Her language deficit makes it difficult for her to handle "that part of life," as she calls it, because she often misunderstands what people say to her, and has difficulty making others understand what she means. Many girls encounter the same sexual dangers as Lori, but they usually have more verbal capability to defend themselves. In addition, her approach to people is often naive. Recently, she smiled at a man in an elevator, and she said that he told her she had better watch out because she might get raped. She was so frightened that the next time she went to lunch with her father and stepmother, her perception of the afternoon was quite different from her father's and stepmother's. She felt she shouldn't have kissed her father and thought her stepmother was judging her. Even though her parents didn't find it different from their other visits, guilt from past experiences flooded her mind and she went into a depression and perseveration of thoughts that her companion, her companion's daughter, two companion program counselors, her therapist, her neurologist, and her father and stepmother have not been able to lift.

Frequent Problems with Expressing Sexuality. Concern over sex was mentioned by both outliers and participants on the regression line.

Lori's problems with sex are evident; she feels violated, guilty, angry and she perseverates on the thought that she is a "dirty person." She says that her body wants sex but that her mind does not. The depression that results from this turmoil prevents her from achieving the independent status that her intelligence would otherwise allow her to achieve.

Donald also has overt sexual problems. While being interviewed, his techer asked, without prompting, if there was anything in the 1959 interview that mentioned they were afraid that Donald would harm a little girl. She explained that he went through an experimental time where he would look under little girls' dresses. When the teacher figured out why he was getting down on the floor, she required him to either be in his chair or sit on the floor facing her. When it came time for Donald to move on to junior high school, the teachers felt he was "too curious about too many things in life that hadn't been taught to him properly. His was not a healthy curiosity....even retarded youngsters learn about the birds and bees. They laugh and joke about it; it's healthy, but we felt Donald would have to be watched." Their fears seemed to have been borne out, for when Donald was thirty-eight, the board of directors of the workshop and group home where he had been living and working decided that his social behavior was inappropriate for their facilities. They indicated that he was a sexually troubled young man.

Anna and Susan have female problems that have caused them pain. Anna finds sex painful and she has not been able to conceive a child, which is her primary dissatisfaction with her life. Susan's female

problems started at puberty and were a major reason for her dropping out of high school. Finally, she had a hysterectomy.

In addition to being concerned about her female problems, Susan seems obviously concerned about her own sexuality. She mentioned two boyfriends that she had in almost every private conversation with the participant-observer. She spoke in hushed tones, indicating that sex is a taboo subject. When Susan dated, either her mother or the boy's mother controlled their sexual activity. Usually, her parents drove her and her date to and from wherever they were going, but sometimes she was alone with a boyfriend. Even then, her mother's admonitions were with her. Susan says, telling about one date, "He called me up and we met at the shopping center. He lived in an apartment over there. He wanted me to come over and go swimming, but my mother said, 'No.' He might want to do bad things at his apartment and I wouldn't want to do bad things." Susan spoke softly when she said "bad things."

Susan's mother feels sad because she thinks Susan misses not having a husband and children, but she says that Susan sees the problems that marriage brings by observing her brothers and sisters and realizes that she could not cope with marriage.

Susan's teacher explained Susan's predicament in a different way. She remarked that she knew that Susan dated some, but that her parents thought it best that she not. The teacher said that Susan was one of the largest children in the class and that her mother worried early about Susan's having a child, because her mother did not want to spend her life rearing Susan's child. Bobby's mother worried about his fathering a child also. She felt he would not be able to support or

take care of one. He dated in high school, but his parents always drove him and his date to and from the dance or sports event. When Bobby decided that his girlfriend was too demanding and decided not to date her any more, his parents were relieved. He seems more interested in sports than girls, and his parents prefer that.

Exceptionally Involved Families. All of the families were very involved with their handicapped children, even in the child's adult life. Five of the families were supportive and the sixth family viewed themselves as supportive, but others viewed them as presenting a barrier to their child's progress.

As Steve was growing up, his mother had a constant struggle to see that he had a good education. Her community did not have a program for retarded students, so she had to seek one out. Although Steve's father was ill and could give little support, his brothers filled in, taking extra time to discuss with him topics he could talk about such as music and trips. The family frequently went on little trips together. Steve knew that he was loved and belonged. After he graduated from school, he lived at home and his mother took care of him on a limited income until he was married in his late thirties. One of his teachers who attended the wedding remarked on how supportive both the bride's and groom's families were. Now Steve's mother doesn't see him too often because he is busy with his wife, his work, and his friends from church.

Anna's mother also had a struggle getting help for Anna. When she knew something was wrong, the doctors kept telling her not to worry. When help was finally found, she made sure that Anna got the speech and physical therapy that she needed. Anna's parents even tried to put her

in a special school, but the other students were more handicapped than Anna and she didn't feel comfortable. Anna's parents were not as successful as was Steve's mother, for they never found a satisfactory school placement for her. But when she dropped out of school, they got a good private tutor. Although there is conflict within the family between the sisters, they will defend each other against any outside force. They go places together, and Anna stays with her sister for a week or more at a time.

Bobby's family is also very cohesive. His mother sought proper schooling for him and taught him to ride the bus when he was placed in a class in a different school. She worked hard while he was in secondary school to get him better vocational training, while his father worked with him in their garage workshop. She was instrumental in his getting and keeping the job he has now. Bobby's brother and sister have always included him in their activities. While they were in school, his sister often wanted to take him with her to church socials. She got her degree in special education and taught retarded students for many years. Bobby and his brother are still close and the family goes on vacations together in their trailer.

Lori's family has always been involved with her, but it hasn't provided healthy support until recently. When Lori was young, her father was abusive to her mother and the children, and her mother passively accepted the victim's role, letting her anger and frustration out on the children, covertly. As Lori was growing up, her father defended her against any discipline her mother used and she was "daddy's girl." When her mother and father divorced and her father remarried,

the family, with the help of the stepmother, was able to provide a healthier atmosphere. Her father was no longer abusive. However, Lori's stepfather raped her. Since her mother denies that it happened, Lori feels betrayed. In spite of all of the negative aspects of her family, they are now involved with her in a positive way. Her mother learned of the companion program and, with help from her mother's boss, Lori was accepted into the program. Lori's father and stepmother take her to lunch once a month. When Lori needs to talk, she calls her mother or her brothers. Her sister lives out of state, but has given Lori permission to call her collect. Lori goes with her aunt to visit her grandmother in a nursing home. It seems that there is often a family gathering for a baby shower, wedding, birthday, or other holiday, and Lori is always invited. Although Lori has many emotional problems connected with old family experiences, both of her parents are trying hard to be supportive now.

Susan's family is very supportive and is a close-knit group. Her parents moved from the Midwest to the West so Susan could go to school. There were only institutions for children like Susan in their community, so they left their family, friends, and work and moved to a place where there were classes for Susan and she could live at home. Her mother was her constant advocate at school. She helped the teacher get supplies and equipment for the special class. The teacher said that Susan's mother would "fight Susan's part any minute, but she had a way of making Susan try to stand on her own. I don't know where Susan would be if she hadn't had a parent like Mrs. ____. Maybe she would be nonexistent." Susan's mother taught her household chores so that she was successful in

class when she helped the teacher set the table for cooking class and when she worked in the school cafeteria. She also taught her to do needle work. "It took me two years to teach her the cross stitch," Susan's mother says. Now Susan shows off her beautiful needle work. Susan's brothers or sister are always dropping in on their parents, often with their children. Susan's nieces and nephews climb on her lap and hug her. Susan's sister helps her decorate the house for each holiday, takes her shopping, and teaches her needle work skills. Susan's brother has introduced her to learning by computer and Susan is improving her reading and math skills. Susan's family is extremely cohesive.

One of Donald's counselors said of his parents, "They have presented barriers to effective programs. They are a loving family but overinvolved." This seems to be a consistent estimate of Donald's family. In 1959, when his mother was interviewed, she said that she felt she was the only one who knew how to take care of Donald, and she wouldn't let him out of her sight. She went to work so that he could be more independent. One of the teachers at his elementary school said that his mother appeared to be trying to make him a perfect child so the school would keep him, for his parents had problems getting him into a school. She would be nice and give gifts to the teachers. In spite of her kindness, his teachers thought that she was a cause of his emotional problems, because she would come to school and just wring her hands when they had conferences. She was very tense. His mother pushed him awfully hard in school, always wanting homework. There was too much overseeing. His mother always gave him the right change for his milk.

One of his teachers said, "She never left the chance for him to show you he didn't know. I don't think Donald was ever given a nickel and let buy anything by himself. He might have learned, if he were ever given the opportunity, but we'll never know." Donald's mother took him out of school. She says that the school did not want Donald, but the teacher says that she took him out of school voluntarily. In all fairness to his mother, the school committee had decided that he was not a candidate for high school and was wondering if they should recommend custodial care, but never came to a decision because his behavior changed from week to week. When Donald was nineteen, his mother became even more involved with him. Following the instructions of the trainers in the Delecato method, she worked with him every day for a year. His gains in coordination seemed to stay with him, but his gains in reading disappeared when the instruction stopped. When Donald went to live in a group home, his parents visited him every week to two weeks. At the last contact, he was again living at home.

Factors Distinguishing Those Who Were Doing Better from Those Who Were Doing Worse than Predicted

Observations revealed six factors that were different for those outliers who were doing better than predicted and those outliers who were doing worse than predicted: reliability of IQ, behavior in school, debilitating health or emotional problems, involvement with social services, marital status, and parent report.

Reliability of IQ Assessment. The reliability of IQ assessment was poor for participants doing better than predicted, while it was adequate for those doing worse than predicted.

Although the two participants who were doing better than predicted had recorded IQ's in the moderately to mildly retarded range, they were not identified as retarded in their daily lives. After checking school records, talking with teachers and parents, and observing the outliers, it was apparent that they were not moderately retarded.

When Anna's IQ was last assessed (her full scale score was 44, placing her in the moderately retarded range) she hated school and was constantly truant. She had a previously recorded IQ of 67 that placed her in the mildly retarded range, but, after talking with her, one realizes that she is more articulate and more "with it" than the other subjects. She has a fairly good vocabulary, and her questions and comments show that she understands the subtleties of what is being discussed. When she was asked to sign the consent form, she read it carefully first, and then asked what the tape recordings would be used for. She made sure that her rights were being protected. As we got to know one another she would ask pertinent questions about my life as a friend might. This ability to be interested in things outside of herself was different from the other participants. One evening when I was going to drive her to her sister's house, she stopped before we got in the car and said, "Are you tired? I can stay here....I don't want you to drive if you are tired." Her contributions to our conversations were pertinent and often insightful. She wanted to tell me that parents should let their children try things; even if they fail, they should have the chance to try. She asked if the parents of the others that I was seeing let them do things. I said one of them lived at home, and Anna replied, "Oh, her parents must overprotect her, but she probably

doesn't know anything else so she's probably content." That was a fairly accurate picture. In addition, Anna can do many things at once. The number of activities that Anna must attend to while she is playing bingo belies either of her IQ scores. Her friends are not retarded and do not treat her in a condescending way. Now-a-days, she probably would be considered educationally handicapped rather than retarded.

When Steve's teacher was interviewed, he said that in his over thirty years of teaching retarded children, Steve was one of his brightest students. He estimated his IQ at around 75 in the borderline intelligence range, rather than the 51 that placed him in the moderately to mildly retarded range in the 1959 study. His teacher has stayed in touch with Steve over the years, often running into him at a classical music concert in the nearby city. Steve invited his teacher to his wedding and the teacher attended. "Steve's tastes are above that of a retarded person....mental retardation is behind him; he's not identified now," his teacher remarked. In the teacher's area, there are several small school districts which share services. There is not a program for mentally retarded students in Steve's district, so students are bused to the district in which Steve attended junior high school. The teacher indicated that Steve's school district's testing was not accurate.

In view of the above information, it was decided that the multiple regression equation should be re-run using Anna's higher recorded IQ and the lowest borderline intelligence score for Steve. With these higher IQ's, they did not lie two standard deviations from the regression line and therefore were no longer classified as outliers.

On the other hand, in the case of the bottom outliers, both Susan's and Donald's IQ scores have remained in the moderately to mildly retarded range throughout the years. According to Susan's psychological evaluations, her IQ was 55 at age fourteen and 50 at age seventeen. Her teacher said that the school psychologist used Susan as a picture of a truly retarded child. Her mother said that it took two years to teach her to do a cross stitch or to tie her shoes. Although she printed beautifully, she was still in the pre-primer in the eighth grade. The computer software that Susan now is using to improve her math and reading is for basic vocabulary and arithmetic operations.

Donald, with an IQ of 53, has stayed eligible for group homes and sheltered workshops over the years. His Regional Center counselors say that he talks very well, but the rest of his functioning doesn't match. He cannot read much, and he can barely write his own name. He has a primary disability of retardation, but he could fool anyone because he speaks extremely well. A teacher at his elementary school said, "Donald was a genuinely retarded and mixed-up child." He had poor retention. His teacher worried about him because she couldn't understand how he could talk so well with adults and not remember that two and one was three. She wondered if his learning problems were emotional or due to brain damage. He didn't progress further than the primer in reading while he was in school. However, his mother continued to work with him and he had progressed to the third grade reading level by the time he was twenty. When a teacher was asked if he could read signs, she replied, "I don't think he could read moons on privy doors." Although he could tell time, his time relationship was poor; if he said he did

something yesterday, it might have been two weeks ago. His mother worried constantly about people's misjudging Donald's abilities, because Donald talked as if he could do anything. It was not until after one had talked with him awhile that his limitations showed.

Behavior in School. The outliers who did better than predicted had behavior problems in school, while those doing worse behaved well.

Anna thought school was a miserable place. Because she was in the special class, the students in regular classes teased her. When her sister came to her defense and a fight ensued, Anna was the center of the uproar. She was more concerned with her peers who rejected her than with her school work. The special class was noisy and was doing work that she felt was beneath her. She did not feel successful in school, and she was unhappy most of the time. Anna wanted to get out of the special class, so when her parents tried to help her with her homework, she refused to do it. She thought that if she failed, they would take her out of the class. It was with this idea that she participated in her evaluations to determine her IQ. When failing didn't work, she started cutting school, and she finally dropped out.

Steve's junior high school teacher said that he was probably placed in the retarded class because of his behavior. "He would rag on kids lower than himself." He had problems with other students. Since Steve looked bright, he also had problems with adults, because they expected too much of him. When Steve's mother requested that he be put in a special class, the school district he was in was probably more than willing to accommodate her by sending him to another district that had a special class, even though Steve was not as slow as the other students in the special class, according to Steve's teacher.

In contrast, the low outliers didn't have these problems. Susan's mother said that when the school psychologist wanted to place her in a special school for the trainably mentally retarded, her teacher came to her defense saying that Susan gave 105% and could make it in the regular program for mentally retarded students. Susan loved helping the teacher, and the teacher would ask Susan to help because she knew things would be done right.

Donald's mother said that he didn't misbehave; she could get him to do anything by talking to him, and his teacher reported similar behavior. He was difficult to teach and sometimes was hyperactive, but he always tried to behave. He never showed a temper at school, but was always polite and gentlemanly, trying to be perfect. He never did anything in the classroom to hurt anyone.

Debilitating Health or Emotional Problems. The outliers who were doing better than predicted certainly had problems in their lives because of their vulnerability to stress and their intellectual limitations, but like the rest of us, they manage a facade of normalcy. Those who were doing worse, however, had overriding problems that interfered time and again with their lives.

Susan's major problem was health. She missed a great deal of school because of her health. It was frustrating to her teacher, for she felt if Susan had attended school more regularly, she would have progressed more. She also wasn't sure whether Susan's mother kept her home unnecessarily or not. When she considered the question, she remembered that Susan did have more colds than the others and she was grateful that Susan wasn't sent to school when she could give her cold

to the rest of the students. Susan's mother says that Susan does not complain too often, so when she does complain, she listens to her. When Susan reached puberty, she began to have more health problems which led to her dropping school before she graduated. Finally, she had a hysterectomy, but she developed adhesions from the operation and had to have another operation to remove the adhesions. Now she has more bad days than good, her mother reports. She gets frequent colds, bladder infections, and has alergies and dental problems. She is very much overweight so her ankles swell when she walks. Most of her family is very large; Susan's grandfather weighed 360 pounds, and her mother weighs 210 pounds. Susan went to a weight reduction program with her mother and teacher, but she got discouraged because even though she ate very little, she did not lose weight. Susan's health problems have interfered with her relationships with men. When telling about one boyfriend's proposing marriage, Susan said, "I wouldn't want to marry him and then find out he didn't love me. He would have to cope with my being sick a lot."

When Susan is compared with other women in the study who have similar IQ's, her handicap score differs from theirs. The others have handicaps that are included on the handicapped scale, such as seizures, speech problems, and difficulty with arm-hand use. Susan shows no handicaps on the handicapped scale. Susan's poor health is not reflected in the prediction equation.

Donald's sexual problems have caused him to be excluded from school, his group home, and his workshop. His teacher felt that his unhealthy sexual curiosity was caused by the way his parents dealt with

the topic of sex. When Donald was twelve, he woke up one morning with an erection and it frightened him because he thought there was something terribly wrong with him. His mother went to pieces and called the doctor. Donald didn't want to go to school, and it took two weeks to a month before he returned. His teacher thought that his dad should have told him that he would feel certain ways or discussed his bodily functions with him. He was blossoming into puberty and didn't know what to do with it. In his adult life, the taboos that deny sexual activity to clients of groups homes and workshops also may have contributued to Donald's seeking sexual outlets in undesirable ways. At the group home where he was living, the clients were watched with binoculars to assure that no sexual activity took place.

Although Donald's sexual problems may not be worse than Lori's, who is on the regression line, she is a victim and he a perpetrator; therefore, the consequences may have graver implications for Donald. People are willing to help Lori, where they merely want to exclude Donald.

Involvement with Social Services. The outliers doing better than predicted have not needed to be involved with social services. Steve works two jobs and his wife also works, so they are able to support themselves. Anna is married to a nonhandicapped man and he supports her while she keeps house.

The outliers doing worse than predicted are not able to support themselves and therefore get a Supplemental Security Income (SSI). Since Susan lives at home and does not go to a workshop, her only involvement with the social service system is to have her case

re-evaluated every now and then. Donald has been a client of the Regional Center, has lived in a group home, and worked in a sheltered workshop and is therefore heavily involved with the social service system.

Marital Status. The outliers above the regression line were married, while the outliers below the regression line were not.

Accuracy of P-A-C 2 Parent Assessment. Mothers of the outliers doing better than predicted responded accurately to the P-A-C 2 questions according to the behavioral observations of the participant observers, while the mothers of those doing worse than predicted underestimated their children's functioning on the P-A-C 2.

In order to find out if Susan and Donald would still be outliers if more accurate P-A-C 2 scores were used in the prediction equation, another multiple regression analysis was run, substituting the observed P-A-C 2 scores. Susan and Donald remained outliers even when the higher P-A-C 2 scores were used in the prediction equation.

It appeared that Susan's and Donald's mothers were less accurate for different reasons. Striving for accuracy, Susan's mother did not say that Susan could perform a task unless she had seen her do it. For example, Susan was able to read two items on a menu. Her mother hadn't the opportunity to observe this because when Susan and her mother go out to eat, Susan always orders the same as her mother. Therefore, her mother responded that Susan could not read two items from a menu.

Donald's mother was so worried that his ability to talk would make others think that he could do more than he was able that she tended to minimize what he could do. In addition, since he was not living at

home, there were items that she had not observed his doing, such as answering the telephone politely and taking a message. His counselor had observed his telephone etiquette and said that he was able to perform this task.

Comparison of the Outliers to the Cases on the Regression Line

Upon examining the cases on the regression line, the only factor that distinguished them from both sets of outliers was IQ assessment. They both were assessed as having borderline intelligence, while the positive and negative outliers were initially assessed as moderately and mildly retarded, respectively. However, as noted in the section on IQ reliability above, the upper outliers are probably more correctly viewed as at borderline or average intelligence levels.

Conclusions

The purpose of this study was to determine what caused the outlier status of those retarded persons that fell two standard deviations above or below a regression line predicting life adjustment. It was expected that a particular parenting style, socialization or educational process, or perhaps the presence of a benefactor would account for this outlier status. However, faulty evaluation that placed the top outliers in categories far below their intellectual level accounted for the outlier status of those who were above the regression line. Imperfect measures that did not account for the degree of handicap of the participants seemed to be responsible for the outlier status of those participants that fell two standard deviations below the regression line.

However, upon examining both the outlier comparisons and the Life Histories, some conclusions can be drawn about the five issues addressed in this study.

The Adequacy of the Americanized P-A-C 2

Mothers Assess Their Children Accurately. Although the mothers of the bottom outliers tended to underestimate their children's skills on the P-A-C 2, their assessments were still quite accurate. Donald's mother answered 96 percent of the items on the P-A-C 2 the same as Donald's workshop counselor. Susan's mother answered 88 percent of the items on the P-A-C 2 accurately as verified by observing Susan's behavior. The other five mothers were between 95 and 100 percent accurate as verified by the participant-observers.

Susan's mother contends that mothers have a sensitivity to their children and if they learn to listen to themselves and their children they will be directed correctly. Anna's, Susan's, Bobby's, and Donald's mothers knew that there was something wrong with their children from birth, and yet their physicians assured them that their children were all right. The mothers of Anna, Susan, and Donald kept taking their children to the doctor, not to disprove their child's retardation, but to receive confirmation that their feelings about their children were accurate. Susan's continued growth in learning has verified her mother's belief that she was educable. Certainly Rod's mother was correct when she told the school authorities that her son was not retarded even though he couldn't put on his coat or hold a pencil correctly. Most of the behavior described by the mothers in 1959 could still be readily observed in their children in 1985. Susan was a sweet,

highly sensitive, empathetic person; you couldn't tell that anything was wrong with Anna by looking at her or by talking to her; Lori does have temper tantrums; Donald is articulate; Bobby can easily use public transportation.

This research found doctors, school psychologists, principals, and social service workers ignoring mothers' fears and convictions about their children. Susan is a prime example. Susan's speech developed late; she had a language of her own, and when she talked, she sounded as a deaf person might, yet only the psychologist's report when she was seventeen picked up her severe auditory deficit, and he made no recommendations to remediate or compensate for it. A previous psychologist's report recommeded that her socialization be enhanced through discussion groups. Had they listened carefully to Susan's mother, Susan's specific problem might have been recognized in time to plan her education differently. A step was taken in the right direction when legislation required that the educational plan for students with learning problems be made with the parents present. Unfortunately, as the school psychologists, special education teachers, and resource specialist teachers conduct meetings in a tight time schedule, the parents presence is often ornamental. Time has verified these mothers' early perceptions and sugests that authorities listen more carefully when they tell about their children. This conclusion agrees with Doernberg's presentation at the World Congress on Mental Retardation (1982).

The Americanized P-A-C 2. Since the mothers in the study had assessed their children quite accurately, The Americaned P-A-C 2 was

useful in determining skills that the participants needed to learn. The P-A-C 2 has features that neither the AAMD Adaptive Behavior Scale nor the 1984 Vineland Adaptive Behavior Scale include. It has more details in some areas and can be useful in determining learning goals. For example, it can make a more specific assessment regarding money; it includes counting it, making change with various denmominations and adding two sums of money together, while the other two instruments determine only if the person can make change or not. The present study, however, indicates that the Americanized P-A-C 2 would have to have new norms estabished for an American population living in the community because most scores of the participants in this study were higher than persons of their intellectual level in Great Britain where the original P-A-C 2 was normed.

The Adequacy of the Prediction Equation

The Objective Measures Collected in 1959 and 1983 Did Not Predict Long Term Adjustment of the Persons Observed. The prediction equation using the P-A-C 2 score as the dependent variable, and IQ, handicap, and home environment as independent variables seemed to predict long term adjustment. When the multiple regression analysis was run, the results looked quite promising. For example. among the seventy cases. only four were two or more standard deviations from the regression line. And even in the case of these outliers, when their predictor variable scores were examined to find why two were doing better than predicted and two were doing worse than predicted, it turned out that their scores had been inaccurate. Field notes on the outlier participants revealed that both of the top outliers, Steve and Anna, had behavior problems in school and

their IQ's had been underestimated. When the multiple regression analysis was re-run using the higher IQ scores, they were no longer two standard deviations above the regression line. Thus, correction of IQ scores enhanced the prediction in the case of these outliers. Although, on the surface, the regression model seemed to predict adjustment, further examination raised more doubts. For example, the field notes revealed that IQ was not a reliable criterion for labeling five of the seven persons studied, There was a sixty-six point difference between Rod's IQ at age six and his IQ at age 32. There was a twenty-three point difference in Anna's two IQ scores. The tests were administered only three years apart in secondary school. Since her lowest score was the most recent, practice was not a factor. Lori was given intelligence tests in 1951, 1954, 1956, and 1957. Her scores were 90, 86, 88, and 72. Here again, there is a variation of more than one standard deviation in IQ score. Even Susan, who had an almost constant IQ score in school years, responded to a relaxed atmosphere and a familiar evaluator with a seventeen point increase in IQ. Steve's teacher, who had taught retarded children for thirty-five years, felt that his recorded IQ score was at least twenty points too low. Labeling a person mentally retarded has far too serious consequences to base the label, substantially on evidence from an instrument that is so influenced by factors other than learning ability. Although the American Association on Mental Defficiency (Grossman, 1983) and the American Psychiatric Association (DSM III, 1980) use IQ as one of their criteria for defining mental retardation, this study's findings suggest that more attention be given to the validity of the method of defining mental retardation. The study

of these seven persons over a period of twenty-five years suggests that their IQ's were not stable enough to inspire much confidence in their accuracy.

Another problem lay in the scales used for the handicap score. The handicap score used categories and a scoring system from the American Association on Mental Deficiency's Classification Manual (Grossman, 1977). These categories, ambulation, vision, hearing, speech, arm-hand use, spasticity, seizures, psychiatric impairment, and, (from the P-A-C 2 assessment) appearance, are ones usually associated with mental retardation. Susan, a bottom outlier, had no handicaps included in these categories. When she was compared to other women with similar IQ's from the initial group of seventy cases, she was the only one who did not have a handicap included in the handicap score. Again, a study of the field notes showed that she actually had severe health problems but they did not affect her handicap score. When she reached puberty she had hemorrhaging and intense pain with her periods. She eventually had a hysterectomy, but she still gets bladder infections easily and has other abdominal pains from adhesions and an undiagnosed problem that seems to run in her family. The handicap scale in the Manual did not include this type of handicap. The nature and severity of Donald's sexual problems were also not fully expressed in his handicap score. The handicap variable in the prediction equation was not inclusive enough.

There were also problems with the home environment scores in the 1959 interviews. There was not enough variability or spread in the home environment scores to make home environment a significant predictor variable. Although the mothers were generally honest in their

interviews in 1959, the degree of disharmony or affection was not revealed in that single interview. For example, during the 1959 interviews, both Rod's and Lori's mothers voiced dissatisfaction with the severity of their husband's discipline, but, as recent conversations with the grown children revealed, they had failed to mention in the 1959 interviews that the husbands beat the children.

Finally, although the P-A-C 2 scores gave accurate information on self-help, communication, socialization, and employment skills at one point in time, they did not account for the variablity in the lives of the persons studied. For example, when Lori's mother assessed her in 1983, Lori had just completed training in the companion program, was holding a job caring for a senior citizen, and traveled on buses to other communities for required meetings of the program. In 1984 she had successfully cared for her companion for a year and had begun a program at the local community college for learning disabled students with a goal of taking nurses aide training. But, by the end of 1985, she was living in a board and care home housing lower functioning clients, was afraid to travel on the bus, and spent her days reading the Bible and doing crossword puzzles. Her P-A-C 2 mobility and employment scores would be quite different in 1985 from the earlier scores used in the prediction equation.

In addition, the P-A-C 2 scores did not give a picture of the quality of the persons' lives or accurately take into account the interaction between the child's personal characteristics, the home and community, and the influence of parents, siblings, and other benefactors. An often used criterion of adjustment based on employment,

independence, and not being institutionalized, also, does not capture one's quality of life, which is hard to measure, but not as hard to recognize when being observed in natural settings. Susan is a bottom outlier when measured with these objective criteria and Lori is on the regression line, but Lori's life is unstable and she is often depressed and fearful, while Susan lives comfortably with people she loves taking pride in those things she is able to accomplish. Susan accepts her limitations, wishes for more companionship, but is not lonely, would like to be more active than her health allows, but is not depressed. Susan does not have to live independently and is not employed, but the quality of her life is better and more stable than Lori's who may not live with her parents and must rely on help from the social services for living quarters and employment. Thus, the field observations reveal that the attempt to collect objective measures and predict long term adjustment is really not very successful and does not result in an accurate prediction of long term adjustment as observed in natural settings by a participant observer.

In summary, the regression equation seemed accurate in predicting general overall trends in a population that had been labeled retarded, but if it was to be used in further research, caution is advised. The data used as predictors in the equation would need to be carefully verified. The unstable nature of the predictors and the detailed pattern of adjustment of these persons precluded an adequate assessment of life history causal influences of outlier status.

Accuracy of Mother's Predictions as Compared to the Prediction Equation Used in the Regression Analysis. Unfortunately, in the 1959

interviews, not all the mothers predicted what their child's future would be like, but those who did were generally accurate. Rod's mother said, "He'll have to go to college. I don't think he'll have any problem." Now Rod has his master's degree. Anna's mother expected her to get married and thought that she might be able to do general office work but qualified her statement with, "I don't know if she could." Anna is married and has held jobs only sporadically. Bobby's mother expected that he would live at home for the rest of his life but thought he might be self-supporting. She did not expect that he would ever marry. Bobby is not married, lives at home, and works in competitive employment. Steve's mother predicted that he would find his place in life. She thought that he could be a box boy, stock boy, or work in an ice cream place. He did work in an ice cream store until it went out of business. When asked if he would marry, she replied, "I couldn't say." When asked if he could support a family, she said, "If he could get the right kind of job, I think he could." She explained that he saved his money so she felt he could be self-supporting. Steve is self supporting and did get married. Donald's mother said, "He's going to be with me all my life. I wish he could go out and get a job and get married, but I don't think he will." She also predicted that things would get harder for her because he would want to do things that he would not be able to do like drive a car. She stated emphatically that "My husband and I will never put him in an institution." Donald does move in and out of his parents home when he is excluded from board and care homes and workshops. He is not married or self-supporting and it does seem to get harder as he grows older, but he has not been put in an

institution. These mothers' predictions were accurate because the mothers used intuitive information about their children's abilities and personalities, and, of course, the mothers influenced their children's lives. Since mothers do have a bearing on the outcomes of their children's lives, perhaps their predictions provide a more adequate assessment than the more objective measures used in the prediction equation.

Usefulness of the Prediction Equation. The objective measures used in the prediction equation did explain 39.7 percent of the adjustment criterion. With large samples, this prediction equation could be useful in looking at general trends in the retarded population to plan for numbers and types of educational and social services needed in the future.

Other objective data collected from the 1983 parent interviews such as employment record, degree of independent living, and institutionalization found a large number of the children who had been labeled retarded twenty-five years ago adapting well to adult life in the community. These results compare favorably to previous follow-up studies based on this type of information. (Baller, Charles, Miller, 1966; Cobb, 1972; Saenger, 1957; Tizard, 1975)

Quantitative studies seem to yield consistent results: retarded persons adapt well to community settings. Qualitative research also seems to yield fairly consistent results: retarded persons' lives are too complex and variable to be reduced to simple statements of adapting well or not adapting well in community settings. Qualitative studies report difficulty in predicting adjustment of individuals (Brooks and

Baumeiste, 1977; Cobb, 1972; Edgerton and Bercovici, 1976; Haywood, 1972; McCarver and Craig, 1974; Owhaki, 1974). The method of research seems to have as much bearing on the results as do any of the measures used. Perhaps the method of research should be chosen to suit the purpose of the ~~research~~.

The major lesson to be learned from this study which used both quantitative and qualitative methods is that quantitative methods can be useful for very general planning, but may not be useful in helping specific individuals whose lives are complex and variable.

Perceptions of Quality of Life

Work Was Important to the Participants' Personal Satisfaction. When the participants of this study talked about personal satisfaction, work was most often mentioned as providing it. Anna recalled the jobs she had held with great pride and was eager to get another job. She said, when she spoke of being successful at work, "I can do more than I thought." When Bobby was asked, "What do you like to do? What do you get the most enjoyment out of?" Bobby answered, "Working." Bobby's father made a telling slip during an interview; he said speaking of Bobby, " He wouldn't trade his life for any other job." Lori often talked about the satisfactions that she received from helping others. She said she was so proud of herself having the job in the companion program. She said, " At the end of group therapy, I said I was going to do this kind of work--helping people--and I'm doing it. They [the people in group therapy] didn't think I could, so I've written to them to let them know." Even Susan, who doesn't believe that she could ever work, suggested that she come teach the members of my learning disabled

class how to embroider. When she was able to show me how to teach a left handed student to do a French knot in embroidery and I reported back to her the girls' success because of her help, Susan grinned broadly.

Edgerton and Becovici (1976) following up a mentally retarded poplulation that had been institutionalized, commented, "In 1960-1961, many of the 48 former patients clearly accepted work as the quintessential means of proving themselves to be normal, worthy human beings." These persons were about the same age as the persons in this study are now. However, in 1976, Edgerton and Bercovici found that work no longer dominated the interests of their cohort. Recreation, hobbies, leisure, good times, friends, and family were their major preoccupation. Zetlin and Turner (Edgerton, 1984) also found age to be an important factor in determining a retarded person's self-perceptions. It would be hard to conceive of work's not being of prime importance to Steve, Bobby, Anna, or Lori because this has been their pattern up to middle age and their parents had taught them a very strong work ethic. It will be important to follow them into their sixties to see if they fit the pattern observed by Edgerton and Bercovici and Zetlin and Turner.

Parents' Attitudes Affected the Participants' Perceptions of Quality of Life. At this stage of life, the participant's perception of quality of life did not differ appreciably from their parents'. Work was valued and their lives were not seen as either dreary or marvelous, but something in between. Zetlin and Turner (1984) also found that parental attitudes had a profound effect on the perceptions of their retarded children.

The observation of Edgerton and Bercovici (1976) of differences between retarded clients' and social workers' choice of meals and recreation was not apparent with this group because both retarded clients and social workers articulated the same preferences. However, neither clients nor, most probably, social workers ate what they said they should. Lori was always pleased with herself when she ate healthily and lost weight, but she reverted to a diet of chocolate bars, coca cola, and coffee when she became depressed. For recreation, the participants, for the most part, enjoyed the same activities that they had enjoyed with their families as they were growing up such as travel, camping, bingo, or soap operas. These perceptions of a good life reflect middle class values and do not differ from those of their teachers or social workers. The goals that they strive for appear to be the same as those of other middle class adults in their communities.

Perhaps the difference between the population of this study and the population of Edgerton and Bercovici was not just age, but also the atmosphere in which the participants grew up. Whereas Edgerton and Bercovici's cohort had been institutionalized, the parents of this population had chosen to rear their retarded children at home. Perhaps parents' attitudes had a greater effect on the participants of this study.

When it came to helping the retarded persons implement these middle class goals, sometimes there was a lack of sensitivity on the part of the teacher or social worker to the retarded person's strengths and weaknesses or likes and dislikes that had aversive consequences for the retarded person's quality of life (by anyone's standards). Choosing a

board and care home housing low functioning retarded persons as a vacation spot for Lori after she had been working steadily for two years with a difficult senior citizen in the companion program was the epitome of such insensitivity. Such insensitivity served to sabotage rather than support Lori's middle-class desire to work.

Parents' attitudes in later life may also tend to influence their children to strive less for independence. As parents grow older, they may have less energy to help their children achieve. Donald's mother, after a bout with cancer, doesn't want anything to disturb her peacefulness. As Lori has seen more of her mother and father lately, her enthusiasm for going to school and working seems to be waning. Her father wanted her to live in a board and care home near him. Lori's mother's complete acceptance of Lori's handicap may be influencing her self-concept again. Continued research with these participants is needed to explore this conjecture.

Influences on the Adult Adjustment of the Participants

This study set out to find what critical life events affected the adult adjustment of selected retarded individuals: how IQ, handicaps, personality, and emotions of the retarded person interacted with factors in the home, school, work, and community environments to affect the adjustment of the participants, and if role models, benefactors, opportunites and consequencs affected the adjustment of the participants.

Several types of events in the life history of these persons seemed critical to their adjustment. First, the initial cause of the retardation was a dominant factor. If the condition responsible for the

retardation resulted in severe emotional problems also, then life was much more difficult for both parents and children. Doctors warned Lori's and Donald's parents that Lori and Donald might have temper tantrums because of their brain damage. Both had severe emotional problems and seemed to have the least stable lives. Since all persons who were studied in depth had difficulty coping with stress, and all had either a physical injury or illness resulting in retardation, it is possible that their emotional instability, in part, has a physiological basis. Also, if the trauma that caused the retardation caused a physical disability in addition, then there were more problems for those persons than for ones whose handicap was not apparent. Anna has suffered much teasing and abuse because she had a physical disability also. Although these statements seem obvious, being aware of the possible emotional component that may accompany retardation, can help parents, teachers, and social workers in their observations of their children and in effective interactions with them.

Subsequent health was also a factor important to adjustment. Susan has more of a disability because of her poor physical health than she does because of her poor academic skills. There is no way to know whether her mother is realistic about Susan's ill health or whether she is overprotective. The significant negative correlation between the home environment factor scores (family harmony and father's acceptance, mother's acceptance of retardation, and lack of punitiveness) and the self-help and employment scores on the P-A-C 2 might indicate that Susan's mother influenced her to be unemployed and to be less self-sufficient. Her family is warm, her father accepts her, her mother

accepts her retardation completely, and her parents do not punish harshly. However, Susan's low scores on the P-A-C 2 were communication, socialization, and employment. Her self-help score was high. With Susan's ill health, it is doubtful that she could work at even a workshop because most workshops do not tolerate sporadic attendance. Neither the participant-observer nor Susan's teacher, who knew both Susan and her mother very well, could determine whether Susan would have been better or worse off with less concern from her mother over health and stress.

The type and degree of abuse suffered by the participants also made a difference in life adjustment. Lori who suffered most abuse is doing less well than most of the others. Her therapist feels that the abuse to which she was exposed has been a significant contributor to her mental breakdowns. Abuse is a problem that the general population faces, but it seems to be intensified among mentally handicapped people and needs to be addressed by parents, teachers, and social workers who are involved with mentally handicapped persons.

In addition, school personnel's evaluation of and attitudes toward these individuals made a major difference in their lives. In five cases either a very good teacher played the role of benefactor or a very poor teacher or school administrator contributed to their low self esteem or their quitting school. The evaluation that placed these students in classes for the mentally retarded in some cases were incorrect and certainly affected their lives.

One cannot help but speculate the course of Rod's life if his mother had not been insistent in removing him from the special training

class. Turner (1980) writes the autobiography of a nonretarded man who was caught in the system and accepted other's evaluations of him. He viewed himself as retarded even though he contributed articles to Earth Science Magazine until he was shown results of tests revealing that he had normal intelligence. One also wonders if Rod were six years old today and being evaluated, would he be classified retarded. The answer would most probably be yes because he would not only have an IQ in the retarded range, but he would also fail to meet the adaptive behavior criteria for nonretarded persons. This realization emphasizes the responsibility of those labeling children retarded.

Opportunities to work and to continue learning seemed important to the self-esteem of each person in this study. Anna, Bobby, and Lori all said work was essential to their well being. Even Susan, who did not work, expressed the desire to help others by teaching them her stitchery skills. Having a benefactor sensitive to the retarded person's vulnerability to stress and willing to educate an employer about that vulnerability enabled those who were employed to maintain their jobs.

Finally strong role models and strong, positive family support seemed critical to the life adjustment of all participants in this study. Lori's and Donald's families were least effective and their children are doing less well.

Some of the circumstances from the participants' life histories that contributed to their adjustment have important implications for schools and social services and deserve to be elaborated. The subsequent topics in this section will expand on these circumstances.

These Persons Are Not Different in Kind from Other Persons and Need to Be Treated As Individuals. The persons in this study were not simple people leading simple lives as some believe of those labeled retarded. Anna's marital problems, self doubts, emotional conflicts, satisfactions from work are similar to any woman's. Susan's longing for companionship and love of a mate, yet realization of her own inadequacies and coping weaknesses is not different from many other women. Bobby's preoccupation with sports, love of bicycling, pride in work, and precision in record keeping fits many masculine roles in our culture. No one could deny the complexity of Lori's and Donald's lives with their transitory living and working arrangements and their emotional conflicts. Susan, who had very low academic achievement, could still discuss current politics appropriately and use good judgment about traffic and shopping . Steve's holding two jobs, socializing with friends from church, and enjoyment of classical music is not the picture of a mindless individual whiling away his time. These people are not fundamentally different from the rest of society. Their high level of dependency and vulnerability to stress is not different in kind from others, for all people are dependent to some degree and react adversely to stress. Rather, they are people, who, in a society that emphasizes intellectual functioning, find their problems magnified and consequently have difficulty coping.

This finding agrees with Bogdan and Taylor (1976) who, using the example of Ed Murphy, declared that the assumption that retarded persons are basically different from the rest of us and need to be explained by special theories distinct from those used to explain the behavior of

"normal" people was wrong. Edgerton (Begab and Richardson, 1975) came to a similar conclusion with his example of Sarah.

Interviews with the seventy mothers described problems that arose when schools and social service agencies thought of retarded people apart from the rest of society assigning them specific characteristics that were presumed to apply to all retarded persons. For example, when it was realized that retarded people need not be institutionalized, the goal became normalization for all retarded people as if they were a homogeneous group whose only characteristic was retardation. One mother told of her criminally insane son who had first been institutionalized at age nine when he almost choked a girl. He had been labeled retarded, and when he came of age, he was sent to a board and care home. He hurt three more women and was in and out of jail until he held thirty people at knife point and threw the knife at a policeman. With the help of a social worker, he has again been institutionalized, but his mother is afraid that he might be released and be killed in the next violent incident that he precipitates. She participated in the study hoping to have her story heard.

Another family told of planning for their daughter's future when they would no longer be able to care for her. They had found an institution where she was on a swim team, was continuing her education, and had made friends. The parents were content that she would have a nice life when they were gone. Then their daughter was normalized and sent to a board and care home where the house parents abused her. Her parents found another place for her, but she does not get the recreation that she did in the institution and they are afraid that the caretakers

will die before their daughter. They worry about what her next placement might be.

Another mother had all of her documentation ready when I called for the interview. Her daughter, too, had been caught up in the trend that said all retarded people should live independently and work. She suffered a nervous breakdown trying to fit into the mold set by the social service agencies who were supposed to be her advocates. We will call her daughter Marie. This is Marie's story as told by her mother. "Marie would go to work and get bad headaches and they [those running the work program] would think that she wanted to avoid work, a copout. They would have meetings every month with the counselors from the regional center and counselors from [she named the work program], and I couldn't talk with Marie there. They would talk on the level of job training. They didn't get to your concerns. Marie wasn't treated as an individual. The counselors said they didn't have time to give to each person, only to train and get work for the clients. It's too rigid, not enough personal contact." She spoke of school and social services when she said, "One fact stands out, they [retarded people] can't fit into guidelines. It must be , individualized If I had been listened to, exchanged views, the hospitalization could have been avoided." These parents know that there is no group of people called retarded that can be treated all alike.

Problems of Sexuality and Physical and Mental Abuse Were Prominent. Much current literature addresses the need to deal with the sexuality of retarded persons (Andron and Sturm, 1973; Kaufman, 1980; Whittemore and Koegel, 1978). Our findings confirm the need to address this issue. The

participants have yearnings that they don't understand and don't know what to do with. Their parents have fears of their children's being taken advantage of and have the worry that they might have to raise a grandchild in their older years. Again to address this issue effectively, the individual's needs must be considered. Lori, who is pathologically afraid of her sexual feelings, could benefit from being guided though a course explaining the physiology and psychology of sex. The materials for such a course would be inappropriate for Susan's abilities. Donald, who also has lower abilities, needs to learn what appropriate outlets he might have for his sexual feelings, but materials appropriate for Susan would not address his problems. Anna could benefit from sexual couseling, but again, as a married woman, her problems are different from the rest. Bobby, who has no sex life and seems content, might be harmed by raising the issue; certainly his parents would be disturbed, and he has to live with them. A general course for the retarded on sexuality would not address the needs of the individuals in this study.

The issue of the verbal, physical, and sexual abuse suffered by retarded individuals has not often been addressed in the literature, yet it is an important one. Verbal abuse from peers and neighbors suffered by retarded children and adults contribute to a lower self esteem. If the theory that we are what others think of us has merit, then our participants must feel that they are inferior people because they have certainly been told so throughout their lives. Current educational practice has a goal of mainstreaming (including handicapped children in schools and classes with non handicapped children) as many retarded

children as possible with the philosophy that mainstreaming retarded children in school will help to overcome their being abused by their peers. It is thought that if the retarded are not segregated, others will understand them better and will have an empathy for them, preventing abuse.

Parents in our study had mixed feelings about mainstreaming. Some parents in the 1983 telephone interviews felt that mainstreaming merely sets the retarded person up for more ridicule. There is some literature to support this view (Myers, 1975). Myers found that subjects with IQ's between 49 and 70 in special schools had higher self concepts than low IQ subjects in special classes in a regular school setting or in regular classes. He found no difference in self concept for subjects with IQ's between 71 and 85 in the three class settings. Donald's mother said that when he went to a special school, he had a better self image and suffered less abuse. When he went to a regular school, he was teased and extorted and began not wanting to attend; he learned very little. Yet Susan's mother was glad that Susan was given a chance at a regular school and not sent to a special school. Susan did not suffer the same amount of teasing that Donald did. Donald's physical appearance and different behavior probably contributed to the amount of name calling and teasing. This possibility is supported by the sociometric study of Gottlieb, Semmel, and Veldman (1978). In addition, involved siblings or parents also helped to prevent abuse. At the risk of being repetitious, the problem has no general solution. Donald may have benefitted from being segegated, while Anna would have benefitted from being in a regular classroom with a private tutor and counseling in how to handle

people who try to take advantage of her or tease her. The solutions that Susan's family found were effective, but they may not have worked for Lori who was agressive herself and invited ridicule. Current research does not support the idea that mainstreaming reduces abuse suffered by retarded persons (Kernan, Begab, and Edgerton, 1983). It is an issue that must be studied further.

Physical and sexual abuse is also a compelling issue. The question is raised whether there is more physical and sexual abuse in a retarded population than in the general population. We assume that retarded persons are less able to defend themselves and are therefore more vulnerable to abuse. The participants in this study were often child-like, but they were not children. Most expressed adult desires for intimacy but these desires confused the unmarried participants for they had no outlet. Susan and Lori were both concerned with not being "bad" persons. Where does the responsiblility lie when the retarded person is over twenty-one and has sexual feelings? Clearly, in Lori's case, her step-father had the responsibility not to have intercourse with her even if she were seductive and over age. Her coping mechanisms were not adult, and she was taken advantage of. The question remains, however, how much responsibility should parents take to protect their retarded adult children in sexual matters? Lori was not protected enough and her mental health has suffered. Susan has been well protected, but not prevented from having boy friends. She sees her weight and health as more of a barrier to intimacy than her parents. Here again each family made these decisions according to its personality and values but it would have been helpful for them to have had individual guidance.

Cultural Expectations Are in Conflict With Individual Growth Patterns. Our institutions are set up conveniently so that everyone begins and finishes school at the same time. An individual is expected to be self supporting by his twenties, get married and have a family by his late twenties, increase his job responsibilities and earning power in his thirties, forties, and fifties, and retire in his sixties. There are many exceptions to these expectations; for example, when the economy is bad, we can expect students to stay in school longer and become self supporting at a later time. But, generally few provisions are made for those who don't follow the expected social pattern.

The problems created by this lack of flexibility in our institutions is amplified in a retarded population. Provision has been made for those with learning problems to stay in school until they are twenty-two. But the participants in this study have needed even more time than that to learn their basic skills. Anna learns reading with the help of her husband; Susan uses the computer to continue her education in basic reading and mathmatics; Lori continues to go to a special program for the learning disabled at a local junior college. These participants defy the notion that persons labeled retarded reach a plateau and learn no more. They need provisions for lifelong learning in an atmosphere that is not demeaning. Community colleges in southern California have begun programs for the learning disabled, but they exclude those labeled mentally retarded.

Acknowledging the inappropriate education afforded retarded persons, Stern (1971) suggests that intensive one-to-one teaching be given to retarded persons when they are 12 to help them master their

basic skills. He further suggests that they spend their high school years in job training, not trying to pass courses in a regular high school curriculum. This proposal is similar to the suggestion of the parents of our participants, especially the second part suggesting job training. However, the participants themselves and their parents acknowledge that the participants' learning ability seemed to increase in their twenties. Lori says she was more motivated and had more self-confidence as she grew older; Susan's mother says Susan was able to retain more and learn more easily as she matured. Their experience does not support the practicality of mastering basic skills at the age of twelve. Therefore, provision should be made for continuing basic skills in education as they mature.

Another expectation has to do with increased job responsibility. Our participants do not fit the pattern of continued growth in the social skills required for increased responsibility in their jobs. Their vulnerability to stress played a large role in their inability to cope with increased responsibility. They have been content to stay with jobs that do not require quick decision making and once learned can be performed with success in a friendly atmosphere. When well meaning employers tried to help by promoting them, their good intensions ended in disaster. As regional centers or other social services plan job training programs, they should include education of employers to the needs of employees who have mental handicaps. Again, these needs will vary with each employee. Awareness on the part of foremen or supervisors to the individual employee's needs will bemefit the company with a good contientious worker many times.

Those Depending on Social Services Had Less Stable Lives. Edgerton and Bercovici (1976) postulated that retarded persons' lives were less stable because they had less control over their life circumstances through savings, job security, retirement plans, health insurance, and networks of friends and relatives. The observations in the present study revealed less stability in the lives of those who depended on social service agencies for work or living quarters for many of these same reasons. Although Susan received SSI, she had stability because she lived with her parents and had a continuity of contact with persons who helped her make decisions and indeed, who made major decisions for her. But Lori and Donald were literally at the mercy of changing counselors or boards of directors who could give or take work or living quarters away. Their recent lives illustrate this point. Lori's regional center counselor, because of poor judgment and lack of resources precipitated a chain of events that returned Lori to a mental hospital. When Lori went to the mental hospital, her regional center counselor decided that she was not developmentally disabled but mentally disturbed and not entitled to services. She was released from the hospital prematurely because Medi-Cal would pay for no more hospitalization. The social worker at the hospital had a difficult time finding a placement for her because the regional center withdrew support and her SSI was insufficient to cover the cost of a board and care home since the amount had been reduced because she had been working previously. Finally, her doctor wrote to the regional center describing her seizures and disability and the center reinstated her. They placed her in a group home which is inappropriate, and, at present, she is

going through the red tape that it takes to change the place where she lives. At the group home where Donald was living, the workers used binoculars to make sure the clients of the group home did not engage in any sexual activity. When Donald got in trouble with the police for some offense that involved sex, the board of directors of the workshop and group home voted to exclude him from their program. Clearly, both Lori and Donald have little control over their own lives.

It must be mentioned that those who did not use the social service system, Steve, Anna, and Bobby all had supportive families and benefactors. Steve and Bobby worked competitively, but had had help in securing their jobs and keeping them. Steve had a wife who contributed to their support. Anna, also, was married and had the support of both her husband and her family. Lori and Donald's families were involved but were less able to cope with their children's problems. In addition, Lori and Donald had severe emotional problems that contributed to the instability of their lives.

In the group studied, those who needed social services were the less stable ones with the least effective support. Our observations show that the lack of time, resources, and competent personnel in the social services further contributed to the participants' instability.

Retardation Involves the Whole Family. Retardation does not affect only the retarded person. This statement may seem self-evident, but often, schools or social service agencies in playing an advacacy role for retarded person did so at the expense of the family. Susan's and Bobby's mothers had nervous breakdowns when school personnel were insensitive to their feelings about their children. Susan's mother was

told by the school psychologist, over the phone, that her child was uneducable and should be placed in a school for the trainably mentally retarded. Bobby's mother was told by the principal of his school that her son "had no brains."

Members of each family were affected by and involved with the handicaped child. Donald's mother took tranquilizers because she was so nervous about Donald. All of the parents spent more time and energy than most parents seeking help for their children such as speech and physical therapy and proper school placement. Brothers and sisters were involved more closely with their retarded sibling's life also. Anna's sisters resented being asked to help Anna. Bobby's sister became a teacher for the retarded. Both Bobby's and Susan's parents depend on their other children to care for their retarded brother or sister after the parents die.

The participants' dependence on others causes family involvement to continue throughout the parents' and children's lives. In Susan's and Bobby's adult years, their families have made compromises so that all members of the family could lead lives that suited their values and have the best possible quality. Susan and Bobby gave up some control over their lives and, in return, live comfortably at home. Their parents gave up the freedom that parents often enjoy when all of the children are independent. Their control over their retarded child allows them to enjoy life, in spite of some loss of freedom, because they can prevent calamities and surprises that would make their older years more difficult. Susan and Bobby might be deprived of life's highs and lows experienced by people who have full independence, but they have

brothers, sisters, and parents who love and encourage them, and they enjoy a stable life. Lori's and Donald's parents prefer to have their children live away from home, but they are still continually involved in their lives. Lori s father helps pay for her board and care home and her mother just took her to look at an independent living facility. Donald's parents are constantly involved with decisions concerning every aspect of Donald's life.

Coping with retardation is a problem that the whole family faces and it is the personality of the family that governs how they solve it. Any guidance given parents to help them cope with their retarded child must consider the family personality or it will be useless.

Because of extreme family involvement, parental attitudes may influence not only perceptions of quality of life, but also perceptions of self and the methods of coping with retardation. Zetlin and Turner (1984) found that parental practices and expectations had a primary influence on how their cohort viewed their handicap and on their adult adjustment. They found three basic parenting styles leading to different patterns of adjustment. The first parenting style was realistic and open regarding the handicap. The parents promoted growth within reasonable limits. The second parenting style grew out of an inability to adapt to the handicapped child and the associated stigma. These parents unwittingly encouraged their handicapped children to set unrealistic goals, leading to dissatisfactions with their lives. The third parenting style also grew out of an inability to adapt to the handicapped child and the associated stigma, but resulted in an overprotected environment. This last group of parents led their

handicapped children to strive for routinization, which enabled them to maintain the self-deception of accomplishment.

There are some major differences between Zetlin and Turner's cohort and the cohort of this study. All of Zetlin and Turner's participants were living independently, while the only common characteristic of the participants of this study was that they had all been labeled retarded.

Donald's mother was the only parent from this study who fit one of Zetlin and Turner's patterns. She failed to adapt to Donald's handicap and the associated stigma, and she and Donald colluded to hide it from everyone, including his brothers and sister. Donald's teachers and counselors view him as a very disturbed person.

Bobby leads a routinized life, but it appears to be his way of coping rather than an attempt at self-deception. He readily admits his handicap by showing his handicapped bus pass and associating with other handicapped people.

The major similarity between the findings of Zetlin and Turner and this study is the important role that parents play in the lives of the participants.

Implications for Parents, School Personnel, and Social Workers

Mothers Wanted Help With Their Child's Specific Problem

Rather than general support, the mothers in this study wanted specific directions on how to help their children. Susan's mother benefitted from the speech teacher's summer workshop for mothers giving specific things that she could do with Susan to improve Susan's speech and memory. Donald's mother was willing to spend all day helping Donald

improve his coordination and his basic skills when she had direction. It is unfortunate that she did not have help with parenting skills when Donald was younger so that she could have more skillfully handled his sexual maturation and his need for independence. Lori's mother could have benefitted from instruction on how to handle Lori's temper tantrums and her sexual maturation. Anna's mother laments that she could not get help with Anna's physical and speech problems when they first appeared. These mothers needed more than emotional support; they needed more power to help their children in very concrete ways.

In addition, all of the parents vehemently wished for more vocational training for their children. They wanted courses in high school that prepared their children to hold a job, and felt that this was a failing of the high school curriculum.

Changing the Traditional View of Mental Retardation

An important implication for guiding parents, school personnel, and social workers has to do with their view of mental retardation. Perhaps the old categories of moderate, mild, and borderline intelligence are not useful in predicting learning potential or for planning the education of children who have problems in their development. It may be less harmful and more correct to talk about specific problems. The retarded people in our sample did not all have similar learning disabilities. Some had problems in the ability to understand social situations, while others had difficulty with memory, or the ability to understand what they saw or heard, or the ability to express themselves. The need for financial support did not seem to be a function of the global level of IQ (the criterion for regional center services at

present), but rather depended instead on the degree to which the specific nature of one's problems affected his ability to cope within a particular environmental context, and this varied from time to time, depending on personal characteristics, amount of support from family and benefactors, and the volatility of the environment itself. Feuerstein's (1982) dynamic assessment process in which the retarded person and the professional work together to discover learning potential and areas of deficient mental processes reflect an emerging shift away from fixed global categorization. This shift is reflected in Richardson's (1982) plea for relinquishing old categories and replacing them with functional descriptions. The mechanistic argument that fixed labels are needed to identify those who should receive help and to standardize legislation for funding such persons, insults our capacity for professional judgment and denies our capacity to create ways to serve a population that has obvious needs in our society.

Identifying specific problems and helping parents compensate for or remediate them will give parents a feeling of control over their child's developmental problems. The parents in the present follow-up study wanted this type of help. We must move away from the practice of helping parents accept a label of retardation, which may, in fact, lessen the child's chance to have opportunities to experience and suffer consequences within his level of capacity. We must help parents to be positively supportive, opening opportunities for their children rather than closing off opportunities because of perceived limitations associated with the retardation label.

The courts have ruled that a child must not be placed in a class for the mentally retarded on the basis of IQ alone since IQ may discriminate against minorities. Instructions are given to school psychologists to use IQ sub test scores only to evaluate intellectual and perceptual strengths and weaknesses, but the reality is that school psychologists still rely heavily on IQ scores in deciding to build a case for retardation. Once the child is so labeled, specific problems are often not included in the report to teachers and parents. The results of the present study suggest that it is important that school personnel do not interpret the IQ to mean a certain potential beyond which a child cannot progress. IQ appears to be, at best, a single, rather unstable predictor surrounded by other more potent indicators of future adjustment.

Social workers also need to change their attitudes about persons labeled retarded. The benefits of life long learning need to be recognized. The education of potential employers of persons with disabilities needs to be planned. Being sensitive to each person's desires, needs, strengths, and weaknesses, and learning how to empower him rather than control him is paramount.

A change in legislation would help professionals recognize the trend away from labeling. However, since the legislative process is slow, using university courses and continuing education requirements would be an appropriate place to begin to change attitudes. Requiring students who are learning to work with retarded persons to participate in the life of a person labeled retarded would perhaps lead them to conclusions similar to those found in the current research.

The Importance of Listening

Another important implication for school personnel, and social workers is to learn to listen to parents. Parents, for their part, must listen to and trust their own intuitions about their children; they also must listen to and observe their child. They will have a continuity of information that no one else can duplicate. School personnel and social workers must learn to listen to this rich source of information in order to plan services. Moreover, they must listen to the child as well.

REFERENCES

American Psychiatric Association. 1980. Diagnostic and Statistical Manual of Mental Disorder, Third Edition. Washington, D.C.: APA.

Andron, L., and Sturm, M.L. 1973. "Is 'I do' in the Repertoire of the Retarded?: A Study of the Functioning of Married Retarded Couples." Mental Retardation 11, no. 1: 31-34.

Azam, R. 1973. "From Home to Special School: A Case for Psychological Assessment." Forward Trends, 17, no. 1: 41-48.

Baller, W.R., Charles, D.C., and Miller, E.L. 1966. Mid-Life Attainment of the Mentally Retarded, A Longitudinal Study. Lincoln: The University of Nebraska.

Bandura, A., and Walters, R.H. 1959. Adolescent Aggression. New York: The Ronald Press Company.

Begab, M.J., and Richardson, S.A. 1975. The Mentally Retarded and Society: A Social Science Perspective. Baltimore: University Park Press.

Bogdan, Robert, and Taylor, Steven. 1976. "The Judged, Not the Judges: An Insiders View of Mental Retardation." American Psychologist 31, no. 1: 47-52.

Brooks, P.H., and Baumeister, A. 19 . "Are We Making a Science of Missing the Point? American Journal of Mental Deficiency 8, no. 6: 543-546.

Cobb, H.V. 1972. The Forecast of Fulfillment. New York: Teachers College Press, Columbia University.

Doernberg, N.L. 1982. "Child-Rearing Attitudes of Parents of Developmentally Disabled Preschool Children." Paper delivered at the 6th Congress of the International Association of the Scientific Study of Mental Retardation, Toronto, 24 August 1982.

Doll, E.A. 1965. Vineland Social Maturity Scale. Minneapolis, MN: American Guidance Service, Inc.

Edgerton, R.B. 1967. The Cloak of Competence. Berkeley: University of California Press.

Edgerton, R.B. 1975. "Issues Relating to the Quality of Life Among Mentally Retarded Persons." In Begab and Richardson (eds.) The Mentally Retarded and Society: A Social Science Perspective. Baltimore, MD: University Park Press.

Edgerton, R.B., editor. 1984. Lives in Process: Mildly Retarded Adults in a Large City. Monograph No. 6. Washington, D.C.: American Association on Mental Deficiency.

Edgerton, R.B, and Bercovici, S.M. 1976. "The Cloak of Competence: Years Later," American Journal on Mental Deficiency, 80:485-497.

Edgerton, R.B., and Langness, L.L. 1978. "Observing Mentally Retarded Persons in Community Settings: An Anthropological Perspective." In Gene Sackett (ed.), Observing Behavior: Theory and Application in Mental Retardation, Vol. 1, Baltimore, MD: University Park Press.

Ellis, N.R., editor. 1979. Handbook of Mental Deficiency, Psychological Theory, and Research. New Jersey: Lawrence Erlbsum Associates.

Feuerstein, R., Jensen, M., Rand, Y., and Waksman. 1982. "Learning Potential Assessment Device." Paper presented at the 6th Congress of the International Association for the Scientific Study of Mentally Retarded.

Gottlieb, J., Semmel, M.I., and Veldman, D.J. 1978. "Correlates of Social Status Among Mainstreamed Mentally Retarded Children." Journal of Educational Psychology 70:396-405.

Grossman, H.J., editor. 1977. Manual on Terminology and Classification in Mental Retardation. Washington, D.C.: American Association of Mental Deficiency.

Grossman, H.J., ed. 1983. Classification in Mental Retardation. Washington, D.C.: American Association on Mental Deficiency.

Gunzburg, H.C. 1976. Progress Assessment Chart of Social and Personal Development. 4th revised edition. England: SEFA Publications, Ltd.

Gunzburg, H.C. 1980. P-A-C Bulletin Number 3. Stratford upon Avon: SEFA Publications, Ltd.

Gunzburg, H.C. 1982. P-A-C Bulletin Number 4. Stratford upon Avon: SEFA Publications, Ltd.

Haywood, H.C. 1976. "The Ethics of Doing Research...and of Not Doing It." American Journal of Mental Deficiency 81, no. 4: 311-317.

Henshel, A. 1972. The Forgotten Ones. Austin: University of Texas Press.

Jehan, Q., and Qusari, Z. 1981. "A Study of Certain Psycho-Social Characteristics of Mentally Retarded Children" Indian Journal of Clinical Psychology, 8, no. 1: 47-48.

Kaufman, S.Z. 1980. "Research in Progress: A Retarded Daughter Educates Her Mother." The Exceptional Parent 10, no. 6.

Kernan, K.T., Begab, M.J., and Edgerton, M.G. 1983. Environments and Behavior: The Adaptation of Mentally Retarded Persons. Baltimore: University Park Press.

Leichman, N.S. 1962. Parent Attitudesin Rearing Mentally Retarded Children. Sacramento: California State Department of Education.

Mark, J.C. 1953. "The Attitudes of the Mothers of Male Schizophrenics Toward Child Behavior." Journal of Abnormal Social Psychology, 48:185-189.

Meyers, C.E., Nihira, K., and Zetlin, A. 1979. "The Measurement of Adaptive Behavior." In N. Ellis (ed.), Handbook of Mental Deficiency, Psychological Theory and Research. New Jersey: Lawrence Erlbaum Associates, Publishers.

Myers, J.K. 1975. "A Comparison of Achievement and Adjustment of Educable Retardates Placed in Three Different Administrative Arrangements." Ed.D. Dissertation. Ann Arbor, MI: Dissertation Abstracts International.

Nihira, K., Mink, I.T., and Meyers, C.E. 1981. "Relationship Between Home Environment and School Adjustment of TMR Children." American Journal of Mental Deficiency, 86, no. 1: 8-15.

Nihira, K., Foster, R., Shellhaas, M., and Leland, H. 1975. AAMD Adaptive Behavior Scale. Washington, D.C.: American Association on Mental Deficiency.

Ohwaki, S. 1974. "Behavioral Characteristics of Habilitated Retarded Persons." American Journal of Mental Deficiency 79, no. 4: 385-390.

Poznanski, E.O. 1973. "Emotional Issues in Raising Handicapped Children." Rehabilitation Literature, 34, no. 11: 322-326.

Richardson, S.A. 1975. "Reaction to Mental Subnormality." In Begab and Richardson (eds.), The Mentally Retarded and Society: A Social Science Perspective. Baltimore, MD: University Park Press.

Richardson, S.A. 1982. "Patterns of Disabilities in a Mentally Retarded Population Between Ages 16 and 22." Paper presented at the 6th Congress of the International Association for the Scientific Study of Mental Retardation.

Ryan, F.J. 1979. Manual Uniform Client Information. Indianapolis, IN: Division of Mental Retardation and Other Developmental Disabilities.

Saenger, G. 1957. The Adjustment of Severely Retarded Adults in the Community. Albany: New York State Interdepartmental Health Resources Board.

Schaefer, E.S., and Bell, R.Q. 1985. "Development of a Parental Attitude Research Instrument." Child Development, 29, no. 3: 339-361.

Schalock, R.L., and Gadwood, L.S. 1980. Community Living Skills Quick Screening Test. Hastings, NB: Mid-Nebraska Mental Retardation Services.

Schalock, R.L., and Gadwood, L.S. 1981. Vocational Training Quick Screening Test. Hastings, NB: Mid-Nebraska Mental Retardation Services.

Shoben, E.J. Jr. 1949. "The Assessment of Parental Attitudes in Relation to Child Adjustment." Genetic Psychological Monographs, 39, 101-148.

Stern, H.O. 1971. "The Competence of a Mildly Retarded Population," Ph.D. disserttion, University of Southern California.

Tizard, J. 1975. "Longitudinal Studies: Problems and Findings." In Clarke and Clarke (eds.), Mental Deficiency: The Changing Outlook. New York: The Free Press.

Turner, J.M.. 1980. "Yes I am Human: Autobiography of a Retarded Career." Journal of Community Psychology, 8, 3-8.

Whittemore, R.D., and Koegel, P. 1978. "Loving Alone is not Helpful: Sexuality and Social Context Among the Mildly Retarded." Working Paper No. 7, Socio-Behavioral Group, Mental Retardation Research Center, School of Medicine, University of California, Los Angeles.

Zaman, S.S. 1976. "Mother-Child Interactions as a Function of Child's Level of Adjustment and Intelligence." Ph.D. Dissertation. Ann Arbor: Dissertation Abstracts International.

Zetlin, A.G., and Turner, J.L. "Self-Perspectives on Being Handicapped: Stigma and Adjustment." In R. Edgerton (ed.), Lives in Process: Mildly Retarded Adults in a Large City. Monograph No. 6. Washington, D.C.: American Association on Mental Deficiency.

Zetlin, A.G., Turner, J.L., and Winik, L. In press. "Socialization Effects on the Adult Adaptation of Mildly Retarded Persons Living in the Community." In S. Landesman-Dwyer and P. Vietze (eds.), The Impact of Residential Settings on Behavior. Baltimore, MD: University Park Press.

Zigler, E.F., and Harter, S. 1969. "The Socialization of the Mentally Retarded." In D.A. Goslin (ed.), Handbook of Socialization Theory and Research. Chicago, IL: Rand McNally and Company.

Zuckerman, M., and Oltean, M. 1959. "Some Relationships Between Maternal Attitude Factors and Authoritarianism, Personality Needs, Psychopathology, and Self-Acceptance." Child Development, 30, 27-36.

APPENDIX A

LEICHMAN'S 1959 INTERVIEW SCALES AND TABLES

TITLES OF SCALES AND TABLES

Scale Number*	
1	Emotional stress of mother prior to child's birth
2	Concern about difficulties during pregnancy
4	Concern about delivery difficulties
6	Awareness of C's deviations prior to M.R. diagnosis
7	Concern over C's progress in walking
9	Concern over C's progress in talking
11	Help-seeking resulting from C's developmental deviation
13	Acceptance of medical diagnosis by M
15	Satisfaction with approach used by initial diagnostician
16	Concern about C's life expectancy by parents
18	Acceptance of medical diagnosis by F
19	Concern in telling F about the medical diagnosis
25	Realistic appraisal of C's limitations (diagnostic period)
27	Extent to which M has need for additional miscellaneous services
29	Evaluation of competency of doctors and professionals
30	Degree to which infant feeding was a problem
31	Amount of pressure in handling baby's feeding problem
33	Extent of problem in bowel training
34	Amount of pressure in toilet training (bowel training)
35	Extent to which C still needs help with toilet habits
36	Extent of problem with bed-wetting (present)
37	Amount of pressure to stop bed-wetting
38	Permissiveness for going without clothes
39	Amount of pressure applied for modesty
40	Permissiveness for masturbation by M
41	Amount of pressure applied against masturbation by M
42	Degree of C's sex curiosity
43	Feelings about C's later sex problems
46	M's sex anxiety - SUMMARY SCALE
47	Degree to which finding a school was a problem
48	C's readiness to attend school
53	Acceptance of need for special class placement
54	Parental satisfaction with school's approach in placement period
55	Parental satisfaction with psychological report
59	Acceptance of need for special class placement by F
60	Concern in telling father about need for special class placement
65	Appraisal of C's potentialities (special class placement period)
68	Extent to which M has need for additional services
70	Evaluation of professionals related to C's school problems
71	Satisfaction with C's school progress
72	Amount of pressure for school achievement
73	Extent to which C is helped at home with school work

*Note: All scales refer to mother's feelings except where both parents are indicated.
Abbreviations: M=mother; C=child; F=father.
All scale responses are scored on 1 to 5 basis.

Scale Number	
74	C's resistance to attending special class
75	C's difficulties with teachers
76	C's difficulties with classmates
77	Degree to which M is critical of other children in special class
78	How M ranks C in comparison with others in class
79	Degree to which school placement is a problem
80	Degree to which adequacy of school supplies and equipment is a problem
81	Amount of activity shared by special and regular classes
82	Need for integration of special and regular classes
84	Extent to which M has had conferences with teacher
86	Satisfaction with parent-teacher conferences
87	Satisfaction with type of school's report cards
89	Report on accessibility of school personnel
90	Number of home visits by teacher
91	Helpfulness of home visits by teacher
92	Number of class visits by M
93	Extent M is critical of activities observed while visiting C's class
94	Extent of home-school contacts
95	Emphasis placed on academic subject for C to learn
97	Extent to which M thinks special class program should be changed
98	Extent of problem regarding C's transportation to school
99	Degree to which M believes it is helpful to discuss problems with others
101	Extent to which parents' group emphasizes beneficial programs
102	Extent of need for changes in parents' group
104	Degree to which M is involved in parents' group
105	Frequency of M's attendance at parents' group meeting
107	Extent of general discussion of parents' group
109	Leadership of parents' group by parents
110	Degree M feels under pressure to attend parents' group meetings
111	Degree M has received information about placement from parents' group meetings
112	Acceptance and/or awareness of mental retardation
113	Degree M has had difficulties getting dental care for C
115	Extent of nervous mannerisms manifested by C
116	Regularity of medical checkups (present or past)
117	Degree to which care of C has been strain on family finances
118	C's ability to handle money and make purchases
120	C's ability to keep self-occupied
121	Degree of problem as to C's watching too much T.V.
122	Degree of C's activity
123	Extent of M's expectation for C to help at home
124	Extent C is able to take care of own room and own things
125	Degree C contributes to general routine of running house
126	Extent to which C can use public transportation
127	Satisfaction with C's present functioning
128	Amount of enjoyable interaction or affectional demonstrativeness between M and C
129	Extent to which M reads stories to C
130	Extent to which M and C get on each other's nerves
131	Severity of present eating problems
132	Amount of pressure in handling C's feeding problem
133	Degree to which table manners are a problem

Scale Number	
134	Degree C has a problem concerning neatness and cleanliness
135	M's expectations for obedience
136	Extent of problem M has with obedience
137	Flexibility of M in modifying her behavior to meet C's needs
138	F's expectations for obedience
139	Relative level of F's and M's obedience demands
140	Permissiveness for aggression toward parents
141	Amount of aggression within home which C exhibits
142	Severity of punishment meted out to C for aggression against parents
143	Frequency of C's willingness to admit deviations in behavior
144	Extent of C's willingness to admit deviations in behavior when challenged
145	Severity of punishment to C for denying he is guilty of deviation
146	Extent of super-ego in C
147	Frequency with which M spanks C
148	Frequency with which F spanks C
149	Benefit spanking has on C
150	Extent to which caution of fire and sharp instruments has been a problem
151	Concern about C's talking to strangers
152	Concern over C's suggestibility (tempted to do something wrong)
153	Degree with which M keeps track of C
154	Extent M expects C to tell her where he is going and when he will return
155	Restrictions of how far C is allowed from home
156	Amount of supervision C needs
157	Amount of dependency exhibited by C at present
158	Extent to which C wants to be near M
159	M's response to dependency
160	Permissiveness toward dependency
161	C's objections to separation from M
162	Effect of C's difficulties on M's socialization
163	Curtailment of parental social activities
164	Positive F-C interaction
165	Affectional bonds between F and C
166	M-F agreement about child-rearing techniques
167	Extent to which F thinks M too strict in disciplining
168	Degree to which M disapproves of F's mode of disciplining
169	Degree of husband-wife understanding
172	Positive effect of rearing M.R. C on marriage
173	Positive effect of rearing M.R. C on M
174	Degree to which M patterns herself after her own M
175	Evaluation of M's competence in child-rearing as compared with her own mother
176	Degree M feels rearing a M.R. C different from normal C
177	Degree of M's child-rearing anxiety
178	Degree of M's self-esteem
179	Intensity of contact between C and siblings
180	Amount of contact between C and siblings
181	Permissiveness for aggression among siblings
182	Amount of quarreling among siblings
183	Pressure M exerts on normal siblings to share activities of M.R. C
184	Adequacy of M's explanation to other siblings leading to understanding of M.R. C

Scale Number	
185	Difficulty siblings have explaining C's condition to their friends
186	Expectation of problems for siblings because of M.R. C
187	Degree M.R. C has caused problems for siblings
189	Degree siblings have felt neglected because of M.R. C
190	Degree to which family activities have helped M.R. C's growth and development
191	Helpfulness and understanding by grandparents
192	Helpfulness and understanding by relatives
193	Social contacts of parent with neighbors
196	Extent to which neighbors are older people
197	Degree to which acceptance of C by neighbors is a problem
198	M's responsibility to structure positive interactions in neighborhood
202	C's involvement in neighborhood difficulties
204	Concern about C's getting into trouble
205	C's difficulty socializing with boys and girls in neighborhood
207	Degree of C's sociability
208	Extent to which C has difficulty finding friends
209	Parents' permissiveness for aggression with other children
210	Parents' demands for C to be aggressive toward other children
211	Extent M is able to find outside activities for C (open to all)
212	Extent M is able to find outside activities for C (M.R. only)
213	C's participation in community groups (YWCA, YMCA, Scouts, etc.)
214	C's interest in social activities including dating and dancing
215	Degree of anticipation that future will be harder
218	Degree of realistic planning for C's future
219	Parental satisfaction with school's job preparation as help to C
220	Helpfulness of elective classes for C
221	C's participation in on-campus work-experience program
223	C's participation in part-time work
225	Degree of anticipation that C will be self-supporting in some type of semi-skilled work
226	Degree of anticipation of C's capability to engage in adult social relations
227	Degree of anticipation of C's capability of marriage and family support
228	Degree of expectation that C will go into army
229	Degree of expectation that boy will adjust favorably in army
231	Concern over what C will do with time when he stays at home
233	Information about sheltered workshops
234	Contact with sheltered workshops
235	Degree to which placement has been considered
238	Parental acceptance of recommendations on institutionalization
239	Degree of pressure applied to parents to institutionalize child
242	Positive parental attitudes toward institutions, foster homes, and private schools
243	Visiting of institutions, foster homes, and private schools
244	Amount of positive change in regard to ideas about institutionalization
245	Amount of acceptance of M.R. individuals prior to birth of C
246	Level of understanding of retardation prior to birth of M.R. C
247	Extent to which self-blame is a problem to M
248	Extent to which self-blame is a problem to F
249	Parental concern about having more children

Scale Number	
250	Expectation regarding C's growing out of present difficulties
251	Extent of using books or articles to get information about M.R.
252	Extent to which religion has helped M
253	Acceptance by others regarding problem of M.R.
255	Acceptance of C by M
267	Helpfulness of remedial reading for C
268	Helpfulness of speech therapy for C
283	Extent of C's participation in school clubs
284	Extent of C's participation in school athletics
285	Extent of C's participation in school dances

APPENDIX B

CLASSIFICATION OF HANDICAPS

CLASSIFICATION OF HANDICAPS

Ambulation

1 No difficulty in walking
2 Limps or walks unsteadily
3 Walks only when assisted
4 Unable to walk
0 Unknown

If individual is unable to walk (supplemental to ambulation items)

1 Not a bed patient (crawls, uses wheel chair, etc.)
2 Bed patient/crib bound
0 Unknown

Vision (with or without glasses)

1 No difficulty in seeing
2 Some difficulty in seeing
3 Great difficulty in seeing
4 No usable vision
0 Unknown

Hearing (with or without hearing aid)

1 No difficulty in hearing
2 Some difficulty in hearing
3 Great difficulty in hearing
4 No usable hearing
0 Unknown

Speech

1 No difficulty in speaking
2 Mild difficulty in speaking
3 Moderate difficulty in speaking
4 Severe difficulty in speaking
0 Unknown

Arm-Hand Use

1 Full use (both hands and arms)
2 Requires some help
3 Requires much help
4 No use
0 Unknown

Spasticity

1 Not spastic
2 Mildly spastic
3 Moderately spastic
4 Severely spastic
0 Unknown

Seizures

1 No history of seizures and none observed
2 History of seizures, but none observed in last two years
3 Seizures observed in last two years
4 Severe seizures
0 Unknown

Appearance

1 Appears normal
2 Passable
3 Conspicuous
4 Very conspicuous
0 Unknown

Psychiatric Impairment

1 None
2 Mild
3 Moderate
4 Severe
0 Unknown

APPENDIX C

1959 INTERVIEW SCALES PERTAINING TO HOME ENVIRONMENT

Amount of Warmth Toward Child

Scale 128 Amount of affectional demonstrativeness or enjoyable interaction (mother to child)

Scale 164 Father-child interaction

Scale 165 Affectional bonds, father to child

Lack of Punitiveness

Scale 31 Severity of mother's handling of baby's feeding problem

Scale 34 Severity of toilet training (bowel training)

Scale 37 Severity of toilet training (bed wetting)

Scale 39 Amount of pressure mother has applied for modesty.

Scale 41 Severity of pressure applied against masturbation

Scale 132 Severity of mother's handling of feeding problems (older child)

Scale 145 Severity of punishment which has been meted out to child for denying that he is guilty of deviation

Scale 147 How often does mother spank child

Scale 148 How often does father spank child

Harmonious Family

Scale 130 Extent to which mother and child get on each other's nerves

Scale 166 Mother-father agreement about child rearing techniques

Scale 167 Does husband think wife too strict or not strict enough

Scale 168 Degree to which wife disapproves of husband's mode of discipline

Scale 182 Amount of quarreling among siblings

Scale 190 Degree to which family does things together that have been helpful for mentally retarded child's growth and development

Scale 191 Helpfulness and understanding by grandparents

Scale 192 Helpfulness and understanding by relatives

Scale 136 How much of a problem does mother have with obedience

Scale 169 Husband-wife degree of understanding

Scale 172 Effect of raising mentally retarded child on marriage.

Acceptance of Retardation

Scale 25 Mother's realistic appraisal of child's potentialities and limitations (diagnostic period)

Scale 65 Mother's realistic appraisal of child's potentialities and limitations (placement period)

Scale 112 Acceptance and/or awareness of mental retardation

Encouragement of Learning

Scale 73 Extent to which child is helped at home with school work

Scale 94 Extent of home-school contact

Parent Receiving Support From a Parent Group

Scale 101 Extent to which mother feels parents' group meetings emphasize the things she considers most beneficial

Scale 105 Mother's attendance at parents' group meetings

APPENDIX D

HOME ENVIRONMENT FACTOR SCORES

Factor Scores from 1959 Interview Scales Pertaining to Home Environment

Participants	Home environment factor scores		
	Family harmony and father's acceptance	Mother's acceptance of retardation	Lack of punitiveness
Top Outliers			
Steve	14.749	1.931	4.230
Anna	11.567	1.449	3.720
Bottom Outliers			
Susan	12.885	2.414	4.139
Donald	12.694	1.932	4.139
Or Regression line			
Lori	10.680	1.931	4.230
Bobby	11.612	2.414	4.139

APPENDIX E

SAMPLE QUESTIONS FROM THE PROGRESS ASSESSMENT CHART OF SOCIAL AND PERSONAL DEVELOPMENT

TABLE HABITS

1. Uses knife and fork correctly—cuts with knife and picks up food with a fork.

2. Table manners—could you take him (her) to a restaurant and be comfortable with his (her) table manners?

41. Takes care of himself (herself) at the table—takes sensible quantities and eats in a reasonably neat fashion.

42. Pours milk or tea into a glass or cup without spilling.

81. Peels fruit with a knife without cutting himself (herself) or cuts a neat slice of bread.

82. Self-service restaurant or cafeteria—can, without help, choose a meal, get a knife, fork and spoon, and pay at the cash register. (Doesn't have to know if he (she) gets the right change.)

CLEANLINESS

3. Keeps hair so it looks brushed and tidied.

4. Hands, face and teeth—Does he (she) know when to wash hands and face; does he (she) use soap and towel and replace them; brush his (her) teeth every day.

43. Without being told, takes bath or shower with soap by himself (herself) frequently enough so that it is pleasant to be around him (her).

44. Man—shaves every day (light beard every other day) without help and looks after razor.
Woman—prepares for her period, copes with bleeding without much mess, and disposes of pads or tampons in trash.

83. Washes own hair without being told and has it cut when necessary.

84. Knows when finger and toe nails need cutting and trims them without cutting himself (herself).

CARE OF CLOTHES

5. Chooses clothes suitable for the weather by himself (herself)—a raincoat when it's raining, a coat when it's cold, or cool clothes in summer.

6. Can tie a bow without looking.

73. Goes to dances and does dance.

74. Goes to club or organization meetings and makes some contribution to the meeting.

113. Takes an active part in an organized group activity, such as bowling or other team sport.

114. Has a hobby, such as collecting, fishing, knitting, etc.

RATINGS OF REGULAR (DAILY) WORK PERFORMANCE

Application

35. Works well but only with constant supervision.

75. Works well with little supervision, but makes no effort to find new task when finished.

115. Is industrious, requires little supervision, looks for work to do.

Quality and Accuracy

36. Work is generally acceptable, but requires constant checking.

76. Quite careful work and needs little checking.

116. Careful work and makes few mistakes.

Speed and Output

37. Works slowly, taking more time than necessary, has to be admonished.

77. Works steadily at reasonable speed without much need for encouragement.

117. Works fairly quickly without wasting time, no supervision required.

Reliability

38. Realizes mistakes and stops, but does not take further action.

78. Generally realizes mistakes and asks for advice.

118. Spots mistakes quickly and corrects them if within his (her) ability.

Timekeeping

39. Generally punctual, but needs frequent reminders.

APPENDIX F

SAMPLE ITEMS FROM THE PARENTAL ATTITUDE RESEARCH INSTRUMENT (PARI)
AND THE PARI SCORING SHEET

Parental Attitude Research Instrument, Form IV
(Schaefer and Bell, 1958)

50

Date:_____

INVENTORY OF ATTITUDES ON FAMILY LIFE AND CHILDREN

Read each of the statements below and rate them as follows:

A	a	d	D
strongly agree	mildly agree	mildly disagree	strongly disagree

Draw a circle around the "A" if you strongly agree, around the "a" if you mildly agree, around the "d" if you mildly disagree, and around the "D" if you strongly disagree.

There are no right or wrong answers, so answer according to your own opinion. It is very important to the study that all questions be answered. Many of the statements will seem alike, but all are necessary to show slight differences of opinion.

	AGREE		DISAGREE	
1. Children should be allowed to disagree with their parents if they feel their own ideas are better.	A	a	d	D
2. A good mother should shelter her child from life's little difficulties.	A	a	d	D
3. The home is the only thing that matters to a good mother.	A	a	d	D
4. Some children are just so bad they must be taught to fear adults for their own good.	A	a	d	D
5. Children should realize how much parents have to give up for them.	A	a	d	D
6. You must always keep tight hold of baby during his bath, for in a careless moment he might slip.	A	a	d	D
7. People who think they can get along in marriage without arguments just don't know the facts.	A	a	d	D
8. A child will be grateful later on for strict training.	A	a	d	D

Case Number: _____

Date: _____

PARI SCORING SHEET

Numerical scores for each of the 23 PARI scales are obtained by summing the scores on the 5 items (questions) which comprise that scale. The questionnaire items are arranged in cyclical order; items 1 thru 23 being the first item on each scale, 2 thru 46 the second item, and so on (item 15 being the last, the fifth, item on scale 23).

Each of the 115 questionnaire items is scored on a 4-point Likert scale: 4 for "strongly agree" (A), 3 for "mildly agree" (a), 2 for "mildly disagree" (d), and 1 for "strongly disagree" (D). This provides a range of scores, for each scale, from 5 to 20.

Take item scores from the PARI questionnaire and record them below, then sum them across to obtain the 23 scale scores.

Scale No.	Scale Name	Item Locations and Scores	Scale Score
1	Encouraging Verbalization	1__, 24__, 47__, 70__, 93__	___
2	Fostering Dependency	2__, 25__, 48__, 71__, 94__	___
3	Seclusion of the Mother	3__, 26__, 49__, 72__, 95__	___
4	Breaking the Will	4__, 27__, 50__, 73__, 96__	___
5	Martyrdom	5__, 28__, 51__, 74__, 97__	___
6	Fear of Harming the Baby	6__, 29__, 52__, 75__, 98__	___
7	Marital Conflict	7__, 30__, 53__, 76__, 99__	___
8	Strictness	8__, 31__, 54__, 77__,100__	___
9	Irritability	9__, 32__, 55__, 78__,101__	___
10	Excluding Outside Influences	10__, 33__, 56__, 79__,102__	___
11	Deification	11__, 34__, 57__, 80__,103__	___
12	Suppression of Agression	12__, 35__, 58__, 81__,104__	___
13	Rejection of the Homemaking Role	13__, 36__, 59__, 82__,105__	___
14	Equalitarianism	14__, 37__, 60__, 83__,106__	___
15	Approval of Activity	15__, 38__, 61__, 84__,107__	___
16	Avoidance of Communication	16__, 39__, 62__, 85__,108__	___
17	Inconsiderateness of the Husband	17__, 40__, 63__, 86__,109__	___
18	Suppression of Sex	18__, 41__, 64__, 87__,110__	___
19	Ascendance of the Mother	19__, 42__, 65__, 88__,111__	___
20	Intrusiveness	20__, 43__, 66__, 89__,112__	___
21	Comradeship and Sharing	21__, 44__, 67__, 90__,113__	___
22	Acceleration of Development	22__, 45__, 68__, 91__,114__	___
23	Dependency of the Mother	23__, 46__, 69__, 92__,115__	___

APPENDIX G

SAMPLE OF THE 1985 FOLLOW-UP INTERVIEW SCHEDULE

I. Parent's Perception of Child and Relationship;
Current Status Description

1. What sort of person is _____? (How would you describe in terms of behavior, temperament, character, self-control)

2. What kind of relationship do you have with _____now?

Does _____confide in you?

Does _____ share problems with you?

Does seek help/support from you?

Are you satisfied with the relationship you have now?

3. How has _____'s relationship with you changed over the years? (a whole lot ____somewhat ____a little ____ not at all____)

At what points in _____'s development did changes occur?

Parent's Name _____ Date _____

Participant's Name _____ Interviewer _____

Post-Interview Rating Scale

1. GROWTH-PROMOTION AS A POLICY IN CHILD REARING

Evidence that this respondent believed a parent should help children mature in adaptation, emotion, language, cognition, etc.; evidence of achievement orientation for child vs not helping child mature except for the convenience of the respondent.

5 highly assisting of growth; implementation to help child mature; achievement orientation

4

3 somewhat promotive of growth; some implementation; some demand for achievement

2

1 the only assistance to improve is for the convenience in caretaking; otherwis no help to mature or achieve some independence

2. DOMINANT CONTROL VS. INDULGENCE

Extent to which the parent exhibited control over the child in various ways vs. indulging the child, letting the child have his/her way.

5 Parent dominated the child, set goals, made decisions

4

3 Moderate amount of control exhibited, but child had own way and choices to some extent

2

1 an indulgent, child-dominated home

3. ACCEPTANCE OF HANDICAPPED CHILD

Extent to which parent emotionally accepted the child

5 Strong attachment, deep emotional commitment, separation could be traumatic (but not the overprotective love mentioned in the next item)

4

3 Affection and attachment present but without great ardor; possibly mixed feelings

2

1 No evidence of affection for child

APPENDIX H

INFORMATION ON SEVENTY SUBJECTS
LABELED MENTALLY RETARDED

APPENDIX H. Information on Seventy Subjects Labeled Mentally Retarded

Information on 70 Subjects	1959 IQ				Father's Duncan Socio-economic Index			Sex		1983 Age			Etiology					
	35-49[a] n=2	50-55[b] n=5	56-70[c] n=35	Above 70[d] n=28	Above 70[e] n=6	30-69[f] n=43	Below 30[g] n=21	Male n=38	Female n=32	31-34 n=20	35-38 n=21	39-42 n=27	Prenatal[h] n=15	Perinatal[i] n=15	Infant or Childhood Illness n=8	Unknown Origin n=17	Not Retarded n=6	No Information n=9
Present Residence																		
Parents' home	-	2	15	7	1	17	6	13	11	9	8	7	4	8	3	5	-	4
Institution	-	-	1	-	-	1	-	1	-	1	-	-	1	-	-	-	-	-
Board and care	1	2	2	2	2	5	-	4	3	3	2	2	1	3	-	1	1	1
Supervised independent living	-	1	3	1	-	4	-	1	3	1	1	2	-	1	1	-	-	2
Independent living	1	-	14	17	3	16	14	19	14	6	12	15	9	3	3	11	5	2
Education																		
Did not finish high school	1	1	4	4	-	2	7	4	5	2	2	5	1	2	-	4	1	-
Finished high school	-	3	25	24	6	33	13	30	22	14	16	22	11	11	8	11	5	-
Post secondary	-	-	6	4	2	5	3	4	6	5	3	2	2	1	2	2	2	1
Employment																		
Workshop	1	1	10	5	-	12	4	9	7	5	6	5	2	6	1	4	1	2
Subsidized	-	1	1	1	-	1	-	1	2	2	1	-	-	1	1	-	-	1
Competitive	1	1	28	24	6	33	19	34	20	15	20	22	12	11	5	15	6	7
5 or more years competitive	-	1	13	15	2	21	7	23	6	6	11	11	6	7	2	8	4	5
Marital Status																		
Number having been married	1	1	13	14	2	15	12	18	11	5	10	14	7	2	3	10	4	2
Number having had children	-	-	8	11	1	9	9	10	10	2	8	9	2	1	1	10	4	1

a - Moderately retarded
b - Moderately to mildly retarded
c - Mildly retarded
d - Borderline intelligence
e - Professional and technical
f - Craftsman, clerical, and small business owners
g - Laborers and service workers
h - Infection in mother, heredity, RH factor, chromosomal anomaly, anomalous fetal development
i - Anoxia, forceps injury
j - Encephalitis, meningitis

APPENDIX I

SAMPLE OF SORTED NOTES FROM THE 1983 TELEPHONE INTERVIEWS

Topic is one of the categories created during the data analysis.

Case number is number assigned to each of the 407 cases in the original study done in 1959.

Para stands for the paragraph number in the telephone interview.

TOPIC=2. WORK CASE=15 PARA=32

LINE	TEXT
1	EMPLOYMENT ACCORDING TO FATHER. SHE WENT TO SCHOOL FOR 12 WEEKS TO TRAIN FOR
2	COMPANION PROGRAM. IT IS A PILOT PROGRAM.

TOPIC=2. WORK CASE=18 PARA=2

LINE	TEXT
1	EMPLOYMENT. SHE USED TO WORK IN A CONVELESCENT HOME FOR PAY. SHE WORKED IN
2	THE KITCHEN BUT HER BACK BOTHERED HER SO SHE QUIT. SHE WORKED THERE FOR 5 OR
3	SIX YEARS. SHE NOW WORKS AT AN ELECTRONICS PLACE THAT MAKES THERMOSTATS. SHE
4	HAS BEEN THERE FOR TWO YEARS.

TOPIC=2. WORK CASE=19 PARA=13

LINE	TEXT
1	EMPLOYMENT. SHE WENT BACK TO SCHOOL. SHE WANTS TO BE IN THE MEDICAL FIELD.

TOPIC=2. WORK CASE=19 PARA=21

LINE	TEXT
1	EMPLOYMENT. SHE WANTS TO WORK AT THE CITY OF HOPE.

TOPIC=2. WORK CASE=20 PARA=2

LINE	TEXT
1	EMPLOYMENT. HE HAS HAD THREE JOBS. NON OF WHICH HAS LASTED FOR MORE THAN SIX
2	WEEKS. HE GRADUATED IN 1970 AND IN ABOU 1972 HE GOT A JOB AT THE CAL STATE
3	L.A LIBRARY BUT THEY CUT DOWN ON HELP SO HE WAS LET GO. THEN HE WORKED
4	FOR A SECURITY GUARD SERVICE BUT HE COULDN'T DRIVE SO HE ONLY LASTED 5 OR 6
5	WEEKS. HE GOT A JOB IN FACTORY BUT AFTER 3 WEEKS THEY SOLD THE FACTORY.
6	HE HAD NO JOB TRAINING.

TOPIC=2. WORK CASE=22 PARA=5

LINE	TEXT
1	EMPLOYMENT. NO

TOPIC=2. WORK CASE=23 PARA=2

LINE	TEXT
1	EMPLOYMENT. THERE ARE MANY JOBS SHE COULD HAVE DONE BUT HER MOTHE NEVER WORKED
2	SO THAT HAD AN INFLUENCE ON HER. SHE IS MARRIED WITH A HUSBAND AND CHILDREN.
3	SHE GOT MARRIED WHEN SHE GRADUATED FROM HIGH SCHOOL.

TOPIC=2. WORK CASE=24 PARA=2

LINE	TEXT
1	EMPLOYMENT. SHE HAS BEEN AT SEVERAL SHELTERED WORK SHOPSFROM ECF. SHE WORKED
2	AT GOODWILL BUT IT CLOSED. IT WAS NOT ADMINISTERED WELL. WHEN THE WORKSHOP
3	WAS PRIVATE, IT HAD A HEART. GOODWILL DID NOT ADMINISTER IT WELL.

TOPIC=2. WORK CASE=24 PARA=22

LINE	TEXT
1	EMPLOYMENT. SHE MAKES $20 PER MONTH ATH THE WORK SHOP. SHE DID WORK AS A BUS
2	GIRL BUT SHE WAS TOO SLOW.

TOPIC=2. WORK CASE=25 PARA=2

LINE	TEXT
1	EMPLOYMENT.PARENTING STYLE.PERSONALITY. FOR 8 YEARS HE WAS A CUSTODIAN AT
2	GRANTS. NOW HE WORKS AT UCLA WASHING POTS AND PANS AT THE TREE HOUSE.
3	THE FIRST WEEK WAAS A STRAIN. PEOPLE MADE FUN OF HIM. HE WAS UNDER PRESSURE. HE
4	TOOK THE BUS EVERY MORNING. WE BRIBED HIM WITH HAWAII TO TRY IT FOR ANOTHER WEEK
5	HIS MOTHER SPOKE TO THE BOSS. AFTER THE 2ND.WEEK HE DECIDED TO STAY AND HAS
6	BEEN THERE FOR 9 YEARS.. HE HAD NO VOCATIONAL TRAINING IN SCHOOL.

TOPIC=2. WORK CASE=27 PARA=2

LINE	TEXT
1	EMPLOYMENT. HE IS A CUSTODIAN IN THE POST OFFICE. IT IS A GOOD ENVIRONMENT.
2	HE HAS WORKED THERE 15 YEARS. HE USES THE VAN TO DELIVER SUPPLIES AND HE
3	WOULD SUBSTITUE AT OTHER OFFICES.. HE MOVED EQUIPMENT TO NEW FACILITY.
4	VOC REHAB RECOMMENDED THE POST OFFICE AND TRAINED HIM. (I CAN'T TELL WHETHER
5	THE POST OFFICE OR VOC REHAB TRAINED HIM.)

TOPIC=2. WORK CASE=28 PARA=9

LINE	TEXT
1	EMPLOYMENT. HE WENT TO A SHELTERED WORKSHOP BUT THE OTHERS WERE MORE HANDICAP-
2	PED. THEN HE WENT TO VOC REHAB AND DR. EDINGER IN SAN MARINO.

TOPIC=2. WORK CASE=28 PARA=19

LINE	TEXT
1	EMPLOYMENT. REHAB- SHELTERED WORKSHOP. I THINK NO WORK IS BENEATH YOU.
2	ONE CAN ALWAYS LEARN. BUT HE DID NOT FIT.

APPENDIX J

1959 AND 1983 STANDARD SCORES ON THE
TWENTY-THREE SCALES OF THE PARI

APPENDIX J. 1959 Standard Scores on the PARI*

Scale Number and Name	Two SD Above Regression Line		Two SD Below Regression Line		On Regression Line		With Master's Degree
	Steve	Anna	Donald	Susan	Bobby	Lori	Rod
1. Encouraging verbalization	0.668	0.218	1.118	0.218	1.118	-0.231	-2.479
2. Fostering dependency	-0.984	2.868	0.300	-1.946	2.547	1.584	0.621
3. Seclusion of the mother	-0.459	1.334	1.337	0.439	0.439	1.337	1.038
4. Breaking the will	0.379	2.094	-1.680	-1.680	-0.651	0.722	0.036
5. Martyrdom	-0.165	1.667	-1.264	-1.264	-0.531	0.568	-0.165
6. Fear of harming the baby	-0.391	0.531	1.146	-0.083	0.224	0.224	-0.698
7. Marital conflict	0.989	0.362	-2.458	0.676	-0.265	0.676	0.676
8. Strictness	0.800	1.122	-2.418	1.122	1.122	0.800	-0.809
9. Irritability	0.333	-0.480	-1.294	-0.480	1.418	0.875	-1.294
10. Exluding outside influences	0.883	1.220	-0.466	-0.129	-0.129	0.883	0.208
11. Deification	1.533	0.938	-2.048	1.533	0.938	0.342	0.938
12. Suppression of agression	0.202	2.814	0.929	1.306	0.175	0.552	0.202
13. Rejection of the homemaking role	-0.002	-0.570	-1.705	-0.853	1.417	-0.286	-0.002
14. Equalitarianism	0.263	-1.522	1.602	0.709	0.263	-0.630	-1.076
15. Approval of activity	1.372	1.372	-1.070	0.674	-0.024	-0.373	0.674
16. Avoidance of communication	-0.093	1.412	-0.845	-0.345	-0.469	0.284	0.660
17. Inconsiderateness of husband	0.003	1.140	-1.418	-1.134	-0.281	1.708	1.708
18. Suppression of sex	-0.619	2.215	0.090	-1.327	-1.327	1.152	0.444
19. Ascendance of the mother	-0.155	1.045	0.475	-2.044	1.498	0.790	-0.155
20. Intrusiveness	-0.251	0.680	-1.181	1.301	1.922	0.370	0.060
21. Comradeship and sharing	0.815	0.815	0.294	0.815	0.815	-0.227	-0.748
22. Acceleration of development	-1.113	1.373	1.684	-2.045	1.063	0.752	-0.491
23. Dependency of the mother	0.948	0.346	-1.459	-1.760	1.249	0.647	0.647

*Mean (of 70 cases) = 0; SD = 1

1983 Standard Scores on the PARI*

Scale Number and Name	Two SD Above Regression Line		Two SD Below Regression Line		On Regression Line		With Master's Degree
	Steve	Anna	Donald	Susan	Bobby	Lori	Rod
1. Encouraging verbalization	↑	0.633	↑	-0.428	-0.959	0.102	0.102
2. Fostering dependency		2.356		-0.396	1.805	-0.396	1.255
3. Seclusion of the mother		1.742		0.045	0.894	1.176	-0.521
4. Breaking the will		2.158		-0.960	-0.337	0.287	-0.337
5. Martyrdom		2.427		-0.054	-0.054	-0.054	0.876
6. Fear of harming the baby		-0.325		0.247	0.533	-0.611	1.105
7. Marital conflict		0.185		0.452	0.185	0.452	0.986
8. Strictness		0.147		-0.170	0.147	0.782	0.465
9. Irritability		-0.677		0.830	0.227	-0.375	-0.677
10. Exluding outside influences		1.973		0.406	0.406	0.092	0.406
11. Deification	No 1983 PARI	1.921	No 1983 PARI	0.478	0.478	-0.966	0.189
12. Suppression of agression		1.167		0.827	1.559	-0.827	0.031
13. Rejection of the homemaking role		1.167		-0.686	0.902	0.108	0.108
14. Equalitarianism		0.154		-0.279	-0.279	-1.144	-1.577
15. Approval of activity		1.022		0.407	1.329	0.100	-0.515
16. Avoidance of communication		2.719		0.061	0.726	-0.271	0.061
17. Inconsiderateness of husband		1.881		-1.132	-0.630	-0.128	-0.128
18. Suppression of sex		3.264		-0.221	0.412	-0.221	0.412
19. Ascendance of the mother		1.006		0.203	0.471	-0.368	-0.065
20. Intrusiveness		1.558		0.907	-0.069	-0.719	0.907
21. Comradeship and sharing		0.930		-1.233	0.389	-0.152	-1.774
22. Acceleration of development		1.568		-1.162	0.355	0.355	-0.252
23. Dependency of the mother	↓	1.943	↓	-0.969	0.778	-0.387	0.487

*Mean (of 57 cases) = 0; SD = 1

APPENDIX K

SAMPLE OF SORTED NOTES FROM FIELD OBSERVATIONS

Topic is one of the categories created during the data analysis.

Case number is number assigned to each of the 407 cases in the original study done in 1959. Case 374 is Anna. Case 15 is Lori.

Para is the number of the paragraph in the field notes for that case.

---------- TOPIC:1. HOME-COMMUNITY CASE:374 PARA:81 ----------

LINE	TEXT
14	understand. L. offered to pay for my gas by saying, "How much would you charge
15	for gas?"

---------- TOPIC:1. HOME-COMMUNITY CASE:374 PARA:85 ----------

LINE	TEXT
1	Abilities.Family.Social Graces. L. had planned what she was going to do; she
2	would stay at [redacted] for a week and then her friend would pick her up and take
3	her back to the apartment. Q: What if [redacted] calls? A: He'll just call [redacted].
4	L. had called [redacted], she said, when my car pulled up. As we got in the car to go
5	to the coffee shop, L. said, "Are you tired, Joan? I can stay here. You should
6	have told me if you were tired. I don't want you to drive if you're tired."

---------- TOPIC:1. HOME-COMMUNITY CASE:374 PARA:87 ----------

LINE	TEXT
1	Marriage.Satisfaction.Personality.Health.Self-Perception.Family. L. said "Our
2	marriage is not going too well. It's been this way since we were married.
3	[redacted] has a lot of good things about him, and my family loves him. But just
4	[redacted] isn't enough. I want children. I'll tell him sometimes that I'm bored."
5	Q: It's because of your ovaries? A: Yes, they have infections. When I was
6	first married, I didn't have my period, and I said I'd better go to the doctor to
7	see if I was pregnant, and then I had my period. I just cried and cried. I
8	brought [redacted] [her niece] home, and I just love her--she treats me like a
9	mother. That's why I go down to [redacted], because I want to be with [redacted].
10	I've raised her. If [redacted] left and mother died, I'll be all alone. I want a
11	child to love me. Q: Had you and [redacted] thought of adopting? A: It's [redacted] too
12	late for that. My life is empty. I get this hollow feeling.

---------- TOPIC:1. HOME-COMMUNITY CASE:374 PARA:93 ----------

LINE	TEXT
1	Home.Marriage.Satisfaction. When I interviewed Mrs. V. she said [redacted] had
2	bought a nice used trailer, and he and L. had moved across the street into the
3	trailer park. L. is much happier in the trailer. She still visits her friends,
4	ut the trailer is nicer than the apartment.
5	End of Case 374 Field Notes.

---------- TOPIC:2. WORK CASE:16 PARA:1 ----------

LINE	TEXT
1	Home.Neighborhood.Appearance.Abilities.Language.Memory.School.Work.Health.Social
2	Graces.Home Assistance. When I pulled up in front of the small house [same as
3	[redacted]), someone peeked out of the curtains. I waved. The house was one
4	building away from a corner where there was a bank and druggists, across the
5	street was a market and, later, I was told a couple of blocks from the beauty
6	parlor. S. and the 72-year-old lady she lives with get their hair done once a
7	week. S. had black hair and was wearing black slacks and a black scooped-neck
8	blouse with a print of flowers on it. She was neat-looking with a pretty face.
9	She laughed after each sentence, like a nervous laugh. She asked me about my
10	connection. She thought I had taught her class, and I knew her. She had asked
11	me this on the phone, and I had told her no. I explained that her mother had
12	been interviewed because she was in a special class. She said, "Was I in a
13	special class?" and asked when. I said I would look it up. She said maybe I
14	meant Widney [a special school] which used to be in Gardena, but is over here
15	now. I said yes, that was it. She said she had had seizures and needed the
16	special school and was also slow. "When I was in Banning High, I had seizures."
17	She says she's now on Dilantin and phenobarbital and doxepine[?]. She says
18	she only gets seizures if she gets nervous. "I know when they are coming. Last
19	month I felt like I was going to throw up, and I told [redacted] I was going to lie
20	down. She understands." When I arrived, she wanted to know if I wanted to sit
21	on the couch or at the table in case I wanted to write. I sat on the couch.
22	She sat across in the chair. Betty is teaching S. to cook, and they had the
23	dinner on. They were having baked potatoes, left-over stew [carrots in it], and
24	salad. [redacted] doesn't eat sweets, but S., who is overweight, buys her own.
25	[redacted] says it's her body, and she can do with it what she wants.

---------- TOPIC:2. WORK CASE:16 PARA:3 ----------

LINE	TEXT
1	Abilities.Personality.Work.Friends.Home Assistance.Memory. [redacted] had just had a
2	cataract removed, and today was the first day she could see in a year and a
3	half. She read a Bill: $38. She had been in a home at 17th and Broadway. When
4	she interviewed S., she said, "I've found her." [I need to ask how much she
5	read for [redacted].] She said she hadn't remembered what time I was coming and had
6	to ask [redacted] yesterday. S. got up to check the potatoes and came back out to
7	ask if she should take them out. [redacted] said, "Poke them." While S was out of
8	the room, [redacted] whispered that she had learned to just walk away from S. if S.
9	get angry. S. came back and said the potatoes were done. [redacted] asked if S. had
10	set them above the oven, and S. said no and went back in the kitchen to do it.
11	She laughed and said, yes, she had done it already. [redacted] said that she jokes a
12	lot. S. said she didn't always know when [redacted] was joking. Sometimes she would
13	say something and sometimes not. But if S. got mad and then [redacted] explained,
14	then S. felt better.

APPENDIX L

SAMPLE OF FREQUENCY COUNTS OF GENERAL OBSERVATIONS

Legend: Case 190 is Donald
Case 15 is Lori

Problems with sex = general observation

In 8,8-15: 8 = paragraph number on computer print-out
8-15 = line number on the computer print-out

* = strong affect associated with behavior described in the paragraph

Example of Frequency Counts of General Observations

Case 150

Problems with sex: 8,8-15;9,8-9;10,1-9;11,1-4;9,11-15;18,1-9;11,19-24;
14,1-2;15,1-5;17,11-16;20,1-30
Dependent: 1,6-7;2,8-9;3,1-5;4,12;5,18-22;10,7-8;11,10-12;12,1-4;
14,1-12;16,1-14;19,1-6;20,5-9;23-30;21,1-10;23,1-5;24,12-39;29,1-4,13-15
Abuse: 8,11;17,8-16;19,13-15

Case 15

Dependent: 1,22-23;6,11-12;8,7-8;13,11-12;17,5-11;20,1-17;21,4-21;
21,14-15;22,24-36;27,6-25;28,7-10;30,7-13;32,1-8;46,1-16;53,1-9;55,6-8;5
56;1-5;59,6-10,60,1-14;63,7-30;68,9-10,71,4-7;77,8-10;,82,23-25;84,1-6;
88,3-4,35-36;97,23-24;101,17-18;105,4-9;106,53;112,1-11;116,1-13;
117,15-18;119,5-7;121,14-16;124,16-22;125,30-36;126,7-10;128,1-6;
129,13-15;130,4-6;,11-35;134,14-16;140,1-23;142,1-15;144,9-13;
145,1-12;148,1-6;149,1-11;151,9-11;152,1-18;172,1-21;170,17-19
Sexual abuse: 10,10-11;11,1-9;18,1-22;20,1-17;21,7-8;23,1-14;29,1-10;
36,1-6;38,7-11;41,1-3;45,1-8;56,1-5;66,1-21;72,12-13;82,23-25;91,1-8;
101,7-8;121,1-16;132,3-7;134,1-14;135,1-21*;147,7-9,62,1-3;151,1-10;
156,1-7;167,1-37;168,1-14;170,1-19

To determine the frequency of a general observation, the number of instances had to be compared to the volume of notes on that case since some cases had more notes than others.

APPENDIX M

LIFE HISTORIES

Life History of Anna (Outlier Doing Better Than Predicted)

Anna, a twin, was born into a family of girls. Her father was proud of his four daughters and doted on them. Her mother was a spunky lady with a mind of her own who had been forbidden to date but managed to meet and elope with the barber across the street. The couple had been married over fifty years when Anna's father died.

Anna's mother fell and hit her stomach while she was pregnant with the twins. Their birth was difficult; Anna was born feet first and weighed approximately five pounds. The twins were kept in the hospital for ten days. When Anna came home, her mother knew something was wrong. Anna cried incessantly for the first three months, and wasn't able to hold her bottle at the same age as her twin sister. Anna developed more slowly than her twin sister. She was slow in sitting up and when she began to walk at fifteen months, she dragged one foot. She didn't talk until she was five years old. Her mother told the doctor about Anna's difficulties, but he reassured her that nothing was wrong.

When the family moved to the west coast, the children were seventeen, seven and five. Anna's mother took her to Children's Hospital where a brace, special shoes, physical therapy, and speech therapy were prescribed. Anna started going to speech and physical therapy and improved immediately. Her father took her on his day off, and her mother came home from work to take her on the other days. They both wanted to do as much as they could for her and regretted not having gotten help when she was three. Anna's mother remembers that Children's Hospital checked Anna's brain and found nothing wrong. Anna continued therapy for two years.

When Anna had trouble doing something such as pouring her milk, her mother asked her sisters to do it for her. Her sisters resented having to help her and thought that their mother babied Anna. On the contrary, Anna's mother remembers that Anna did her chores responsibly and was a better help around the house than her sisters. It was important to Anna's mother that her daughters learn independence by doing chores responsibly.

Anna was a warm, outgoing child, and she played with other children in the neighborhood. She went to their houses or they came to hers. She got along well with most of the children, but some of them teased her. Roller skating and riding a bicycle, which her parents encouraged at the

suggestion of Children's Hospital, helped her coordination. She and her twin sister played dolls. Her older sisters did not want the twins tagging along or hanging around them so Anna's dad told the twins to stay home and play with each other. Both parents played games such as checkers with the children.

Anna was not as happy at school as she was at home. Since Anna learned more slowly than the other students, she did not progress. She had trouble especially with reading and writing. She wrote backwards and her hand shook if she got nervous. However, she was smarter than her twin in math and could add numbers in her head.

When Anna was seven or eight years old, her parents decided to enroll her in a special school that could give her more attention than the public school teacher could. Anna didn't like the private school. She was shy, and when they served food, the plate was usually empty when it got to her. She was not as physically handicapped as the other children and she felt out of place. Her mother spoke to the school about Anna's complaints and when nothing was done about them, she put her back in public school. Her mother laments that she didn't get educational help for Anna in the preschool years, but she believed the doctor when he said Anna would be all right.

At the end of the fourth grade, Anna was tested, found to be in the mildly retarded range, and was put in a special class. She didn't like this special class either. She didn't feel she was like the rest of the students in the class, and found it hard to concentrate because of the noise. The children in the regular classes would snatch her lunch or her money and tease her about her speech and being in the special class, so her life at school continued to be miserable.

Anna's mother was aware of the teasing and tried to stop it. She went to the parents of the children who were teasing Anna to ask them to discipline their children. Some parents were rude, saying that they could do nothing about their children's teasing. Anna's mother told them that she wished their child was like Anna, and perhaps they would have more feeling for Anna. Anna's sister also tried to protect her by fighting those that teased Anna.

In junior high school, Anna weighed 185 pounds. She got mostly "D's", but she did graduate in a cap and gown . Her mother was very proud of her. Her twin sister could not pass English so she did not graduate. Anna's most vivid memory of the occasion was that she and her twin sister were the only ones at the graduation dance without dates.

Just before high school, Anna was re-evaluated and her IQ score dropped 23 points. Her score of 44 placed her in the moderately retarded range. She and her twin sister were sent to different high schools because there was no special class at the high school she was supposed to attend. Anna remained in a special class and her sister remained in regular classes.

Anna's mother wanted her to stay in the special class, but Anna hated it. She would not do her homework hoping that she would get kicked out of the special class. Unknown to their mother, the twins were often absent from school. They would meet at Anna's school, go to the park across the street, and at an appropriate time, catch a bus and go home. They wrote their own excuses for being absent, so the school records show forty-three excused absences and only two truancies in two years.

Anna continued to be teased in high school. Her twin came over from her school and fought those who teased her sister. Anna tried to handle the abuse herself, but was ineffective. Once, when a group of girls ganged up on her, she reported it to the principal. He insisted on seeing all of the girls involved, including, Anna in his office. Anna was afraid to be in the same room with those girls, but she complied. The girls said that they didn't recognize Anna, and the principal seemed to believe them. Anna dropped out of school. Her mother, remembering Anna's junior high school graduation, believes that Anna was the only one of her daughters to graduate from high school. Anna's school records show, however, that she dropped out before graduation.

After Anna dropped out of school, her father asked a cousin who had been a professor in Europe to tutor her. Anna says that she learned a great deal from him because he was a good teacher, it was quiet, and she could concentrate.

Anna and her sisters loved their father very much. Although he was not openly affectionate, he took them to brunch on Sundays, gave them pocket money, even if they didn't ask for it, and let them out of their rooms when their mother was punishing them. Anna told us, "He was really good to us, but he was too easy on us. He would say, 'Do you have enough money? Here take some.' He would send us to our room and say, 'You stay there for ten minutes.' Then in a minute or two he'd come in to our room and say, 'Do you think your ten minutes are up?' Of course a child will say yes, and he'd let us out, or he'd say, 'You can't have the car.' and an hour later he'd say,' I think you've been punished enough.' We would hate it if my mom were around. She'd say, 'The ten minutes are not up yet.'" Anna's mother felt that he didn't encourage the girls' independence, and she got angry when he undermined her discipline. She talked to him about it, but he didn't change. Anna gets her criteria for a good father from her childhood experiences: one who is affectionate, but does not let his children get away with anything.

Anna's mother was stricter than her husband. She spanked the children or sent them to their rooms. She recalls that Anna was not treated differently, except that she didn't yell at Anna because Anna was sensitive and would be hurt too much. Anna's mother always wanted to know what her children were doing, so she sent Anna and her twin along when their older sister and her boy friend went to the movies. Anna tells this story, "Mother would say, 'Did you see the movie?' 'No,' we would answer. 'Sis and her boy friend were in the way.' 'What were they doing?' 'Kissing.' Sis would say, 'You're never going with us again.' 'Oh, we was lying,' we'd tell mother."

Anna's mother is strict, quick to tell her children's short comings, defends them fiercely, and comments on their strengths. She says of Anna, "She is lovable and good hearted; you would never know there was anything wrong with her."

After Anna left school, she slimmed down to 116 pounds. She dated and went to dances. At one dance, she met a handsome man named Herb, and they began dating. Other men had taken advantage of her by asking her to pay for the date; Herb did not. After they had been going together for five years, Anna's father told him to either marry Anna or quit seeing her. Herb and Anna were married at a beautiful, formal wedding. Anna thinks that her father must have had a stern talk with her husband-to-be, for he is very protective of her.

Two weeks after she was married, Anna was back home. She was lonesome and bored and sex was painful. Her parents encouraged her to return to Herb, and she is still married to him. She began baking every day to keep herself amused, and found that it also helped to bake when she was angry. "It doesn't turn out so good," she says. "I made sixty pounds of fudge last Christmas." When asked what she did with it, she said that she threw some of it away because it was too hard, but she shared the rest of it with her family. Anna also met neighbors with whom she could socialize. They went to lunch and shopping every week.

When Anna was first married, they lived with her mother-in-law. Her mother-in-law complained that Anna was not right for her son because she drank and was Catholic. She threatened to disown her son if he raised their children as Catholics. Anna told her that if her son drank, it was not because Anna drank, but because he drank. Anna had stood up for herself, and she says that she and her mother-in-law get along fine now. Her sister in-law confided that her mother-in-law had treated her that way, too.

Anna's marriage has had its problems. She loves Herb but she feels he is overprotective. He helps her, and yet he stifles her. He has helped her by encouraging her to learn. If she is reading a newspaper and asks him a word, he helps her sound it out rather than just telling her the word. If it is really too difficult, he will tell her what it is. She has learned that she can do more than she thought she could. Still, he takes care of all of the finances, pays the bills etc. He used to give her only twenty dollars to spend now and then. Anna says that Herb "watches me like a hawk." When Anna wanted a car, Herb bought her a bicycle and wanted her to ride it around the parking lot to make sure she knew how. Anna refused to do it. If she spills something, he yells at her and has embarrassed her in front of her friends. He is also something of a recluse, so they cannot enjoy a social life together. She often goes to stay with her twin sister for weeks at a time. He takes her and picks her up and doesn't seem to mind that she's gone. Yet, she feels that he loves her, because he is protective and defends her if any one treats her rudely.

Anna has worked off and on since before her marriage. Her mother paid her to take care of her grandmother who lived with them, and she did a good job. When her grandmother died, Anna got a job at Goodwill through the

Department of Vocational Rehabilitation. She was asked to put clothes on hangers that were hard for her to open with her weak hand. She would come home from work with a swollen hand. Her mother went to the shop and talked with Anna's boss to ask her if there wasn't another job Anna could do, but the boss said, "No." Anna's mother saw that there was a clothes' sorting job that would be more appropriate for Anna's handicaps but concluded that the boss wanted Anna to quit since she had seen her in the back room changing the prices on some furniture and splitting the profit with the truck drivers. Anna was bright enough to know what was going on. Anna's mother advised her that if she wanted to keep this job she should stay out of the back room.

After Anna was married, her husband helped her fill out job applications and she worked in several places. She packaged hosiery until the mill closed down. She worked at a snack bar, but her hand shook and she broke some coffee cups. There was too much pressure at lunch time, so she quit. Each year, Anna and Herb went to Idaho to be near his family and to hunt. She had a seasonal job there in a cannery and a job in a coffee shop. She liked the coffe shop job very much, but the other waitresses and one regular customer were mean to her so she quit. The customer worked in the bank across the street and brought a different girl to lunch every day. One day he said to Anna, "I don't like the way you dress or talk. Your hand shakes. Don't serve me coffee." "I won't," she replied. When asked what she had been wearing, she answered that she was wearing jeans as were the rest of the waitresses. The other waitresses were younger than Anna, and one day they asked her to meet them in the back room. When she did, they told her that they didn't like the way she talked and told her to quit. When she told her husband about the two incidents, he came down to the coffee shop and sat next to the man who had insulted his wife. The man only said, "Thank you, mam," when Anna served him. She was glad Herb was there to protect her.

Anna's most successful work experience has been as a waitress in her sister-in-law's tavern. Herb and his brother go hunting and leave the tavern for his wife to run. Anna waits on customers and makes change. At first, Anna's sister-in-law didn't think Anna could handle the customers, but Anna has gotten used to them. When they say, "How's about goin out?" she kids back, "What time you pickin me up?" She is thrilled to know that she can do that job well. It makes her feel competent.

Another place where Anna is extremely competent is in the bingo parlor. She goes with her neighbors, her mother and sisters, and when she is in Idaho, with her sister-in-law. She does not tell Herb how much she plays, because he doesn't like gambling. Anna said, "He says he works too damned hard for his money to have it wind up in a bingo parlor. He doesn't know I play bingo as much as I do when I come to visit mother." Her mother and sisters play bingo every week and spend a minimum of $27 per night. The game of bingo, as it is played in bingo parlors, requires the players to do many things at once. While Anna is listening to the number's being called and blocking it off on several cards, (sometimes there is a particular pattern that she must follow such as a "Z" lying on its side) she is also buying cards for the next round and helping her mother see numbers. If she wins, she gets $250, but that does not happen very often. When any member of the family wins, the prize is shared with the others.

Family is very important to Anna. She is very close to her mother and sisters. When her brother-in-law died, she helped her sister-in-law pack and move. She wishes that she had children of her own, but she has a bad ovary and has not gotten pregnant. Her mother would like her to adopt children, but Herb doesn't want to. Anna has become very close to Tina, one of her twin sister's children. Tina stayed with Anna and Herb for a month, and Anna loved taking care of her. She says that one of the reasons she goes to stay at her sister's house is so she can be with Tina. Her sister also has twins and Anna gets along with one of them, but the other one says cruel things to Anna such as"I wish you were dead," and Anna is hurt.

Anna's mother thinks that Anna is a good wife and would make a good mother, but she doesn't think Anna could live on her own. She doesn't think Anna could manage money or get around on her own. Both Anna's mother and husband feel that Anna is too nervous to drive, and she has not been too successful using public transportation to go very far. Once she tried to take a bus to visit her sister and had a terrifying experience. Her sister lives in a community about an hour's drive from Anna's apartment. She had to take one bus into the downtown district of the nearby city and then transfer to another going to her sister's town. She had to change busses in a very bad part of the city and had to walk a few blocks to get from one bus to the other. She got directions to the second bus and found herself walking down an alley. Anna is frightened of black people, and there were two black men in the alley. She was so frightened that she fell down and threw up. She started at two in the afternoon and did not arrive until 7:30 in the evening. Everyone was concerned, and Anna never attempted the trip again.

Anna is also afraid to stay alone. Last summer when she and Herb were supposed to go to Idaho, she kept postponing their departure. He finally left without her. When he had gotten as far as Nevada, he called, and she said that she missed him, and he came back for her. Again, when it was time to leave, she said she didn't want to go. He stormed out of the house at four in the morning,and Anna was embarrassed to let her friends at the apartment know what had happened. Her best friend was out of town. She called the participant-observer in tears, saying she was afraid to stay alone and asking if she could get a ride to her sister's house. She offered to pay for gas. Herb had paid all the bills before he left, had left some money with her, and was to send her more later. Anna was all mixed up; Herb had never gone off like this before and she felt torn. She had talked with her sister before she was going to leave with Herb, and she couldn't bring herself to leave her twin. Anna thought she needed a psychiatrist but she knew Herb would never pay for one. He was adamant about her not telling others about their business. The only other time he had left her was when he found out she had told a girlfriend something that he had said. That time, Herb was gone for three weeks, but he never left the city. Anna made the participant-observer promise that if Herb came back for her while the observer was there, she would say that she had just dropped by; Anna didn't want Herb to know that she told the participant-observer about their business. By the time the observer got to Anna's apartment, her friend had come home and Anna felt better because they had been talking. Anna still wanted to go to her sister's and she stayed there for quite a while.

When Herb returned, he bought Anna a mobile home and they moved to the mobile home park across the street from their old apartment. Anna was delighted to have a place of her own. It was only three years old and very nice. It had a bedroom and a half, a kitchen, bathroom, and a living-dining room combination. They had lived in an industrial area far from any shopping center, and the mobile home was still in that area, but she could go across the street to see her friends from the apartment. He began giving her $400 per month to budget for the household.

Anna and Herb returned to Idaho to visit family and to hunt. Anna stayed in Idaho, while Herb drove the mobile home to Texas to live and work for a while.

Anna Talks About Herself.

The following are ideas that Anna repeated several times or told with intense emotion to the participant-observer.

Speaking of her husband she said, "He shows me kindness and loves me and makes me do things for myself. Mom and Dad would think maybe I couldn't do it. I'd bring home a job application, and they wouldn't explain it to me. They'd say, 'Oh, she doesn't understand it.' If I take it back and they ask me questions I can't answer, that's why I have to understand it. Herb will fill out a job application for me, because my hand shakes, and then I'll sign it." Anna indicated that Herb would explain the application to her. She also tells how he has taught her things. "At first, he would buy all my shoes. I wanted to buy sandals in winter, and Herb insisted I buy closed shoes. Buying sandals in winter was dumb, but I had to learn it."

She goes on to tell some of their problems. "My father must have had a talk with him, and I don't know what he said, but Herb doesn't want me to go out alone, or drive. When I go with my friends, I want to be able to say, I'll drive next time. But Herb wants to teach me to drive, and he wants me to do everything his way." Anna has her drivers license.

"Herb isn't very social. He would just sit home all of the time. I tell him I want to be more social. He says I can if I want, but he doesn't have to." Anna shakes her head as she says this as if she wished Herb could be different.

When Anna talks about having children she gets very emotional, "Herb has a lot of good things about him, and my family loves him, but just Herb isn't enough. I want children. My life is empty. I get this hollow feeling. I'm too old to have a baby now, but I would like to have children. My sisters say they envy me, because I'm free, but I'd rather have kids."

Anna says of her niece, "I just love her; she treats me like a mother. That's why I go down to my sister's, because I want to be with Tina. I've raised her. If Herb left and my mother dies, I'll be all alone. I want a child to love me." She goes on to describe an incident with Herb and her niece in a store. "He likes kids and so do I...If she [Tina] were in a

store and she would beg for something, Herb would tell her she couldn't have it today. If she kept saying, 'I want it,' he would take her pants down and spank her right in front of everyone and then say, 'You wanted that [the item], but you got that [the spanking]. Now which do you want?' She would shake her head neither." Anna felt that Herb was giving Tina love not things.

Anna says, speaking of her family, "My sisters were jealous of me. I didn't know about it. They didn't treat me different than regular. It hurts down inside when sisters feel that way." Her twin had told her that her older sister said she resented Anna. Her twin says that she resented having to help her also. Her twin has been working out her feelings toward Anna in therapy. Anna speaks of her twin, "We get along real good; she never shows me dislike and hate. She still babies me. I get along real well with her husband, and she'll say,'Don't hurt my sister.' I don't like it. I'll say, 'He's not hurting me.'"

Anna says of her mother, "Mother and Lily [her twin] are going to play bingo Saturday night. Mom is playing tonight, so if she wins, she'll treat me Saturday. If not, I'll either have to stay home alone or borrow from Mom to play. I don't want to borrow to play bingo. If we win, we split our winnings with each other. I respect Mom and she's been awfully good to me, but I get so mad at her. Like crossing the street; she's so slow. She doesn't think I'll yell at her. We get on the phone and Herb says, 'Anna, that's your mother you're talking to.' I go into the bedroom to finish the conversation. I can yell at my sister and I don't feel guilty, but if I yell at my mom, I do."

Anna speaks with great pride when she tells of working at her sister-in-law's tavern. "At first, she didn't think I could do it, but now she leaves me alone; I serve beer and wine and make change. It's all in here." She taps her forehead.

Anna shows a lot of her mother's spunk when she speaks about herself and her convictions. "Two weeks after we were married, I was home saying, 'I don't want to be married or have sex.' At home there was always my mom and dad and uncles and sisters. Now I just cleaned house and waited for Herb to come home. I didn't like it. I got used to it. Herb's mother thinks the man wears the pants and works, and the woman cleans up his mess and obeys him. I don't believe that way. I want to be my own person." When asked who her role models have been, Anna replied, "Myself. I'm a very different person from the way I used to be. I used to want to be like my sisters; now I want to be like myself. If my sister says, 'Let me pour the coffee, your hand shakes.' I'll say, 'No.' If I spill the coffee, I do, but I will pour it myself. Don't say I can't do something. Let me try. If I can't , I can't, but I want to try. I have learned I can do more than I thought. If a child trips and falls, getting hurt is not so bad. I don't want to see anyone hurt, but you have to give them the chance to do things. Anyone can do anything, if they want to. If they don't want to do it, they will not be able to."

Life History of Steve (Outlier Doing Better Than Predicted)

Steve's life history is less detailed than some of the others for the participant-observers did not have the opportunity to talk to Steve. Something can be learned from the way his family protected him and his mother. It seems to be a family that sticks together.

When Steve's mother was first asked to participate in the follow-up study, she agreed readily. She was just remarrying when the project began, and she was busy consolidating her new husband's household with her own. When she was more settled, she was pleased to be interviewed and have the chance to tell how well all of her children were doing. She did not like the questions on the Parental Attitude Research Instrument, however, and refused to fill it out after her children encouraged her not to do something that she didn't want to. After she had talked the project over with her children, her attitude changed. She was less enthusiastic and helpful and was more aware of her own needs. She said that she was looking forward to her life with her new husband and wanted to put her past behind her. Raising Steve had been hard, and she did not want to be reminded of it. When Steve became one of the outliers, she refused to put us in touch with him. She was polite, but firm. She was willing to help us get in touch with a teacher that had been an important benefactor for Steve, but she would not help us locate Steve, and made it clear that she did not want him disturbed. At the suggestion of Steve's teacher, Steve was observed at work, for he worked in a public place and just being a customer allowed one to watch him perform his job. Steve's teacher and our observations confirmed that she had been honest in her assessment of Steve and that she most likely did not want him to be associated with a study that would point out his handicap. In her 1959 interview, she mentioned several times that he was normal in every way except learning, and that she expected that he would not be noticed as differeent as he grew older. That seems to be a wish that she still has for him.

The following is Steve's story as gathered from his mother's 1959 and 1983 interviews, interviews with his teacher, and our observations of him at work.

Steve was born third in a family of five. He has a sister four years older and a brother one year older. another sister is seven years younger and a second brother is fifteen years younger.

Steve's father was a letter carrier and his mother stayed home with the children. His mother is not sure if his slowness was caused by a fall when he was five weeks old or an illness when he was nine months old in which he had a high fever and was delerious. As he was growing up, he had several traumas. He caught his arm in the washing machine when he was three, at six he was burned badly enough to shock his nervous system, and at age eight he had a very bad case of the whooping cough. His mother noticed a difference in him after the burn and even more so after the whooping cough. He seemed more nervous. The doctor told her that the whooping cough left him with a temporary condition.

Steve's development was slow from the beginning, however. He was slow to sit up, didn't walk until seventeen months, and when he started to talk, his speech wasn't clear. He wet his bed until he was four, and had problems in school also. In kindergarten, he was annoying and scribbled on or took other children's books. He couldn't learn to read in first grade, but pretended to do so because he wanted very much to be able to read. He repeated the first grade. The second time he took first grade, he had a different teacher and seemed to learn at the pace of the rest of the class. He was in the lowest group in the second grade, and by third grade, he was constantly in trouble. He would get up and go to the window, kick his heels against the desk, and never seemed to know that he had to do his work at a particular time. His mother asked if there was a special class in which he might do better. She was told that there were no special classes in her school district, but that she could take him to a nearby district where special classes were available. She visited the special class, and when she talked it over with personnel at Steve's school, it was agreed that a special class would help him. He would get more individual attention and could learn at his own speed. Steve was nine years old when he began the special class.

In the mean time, his parents were still seeking medical help. They took him to Children's Hospital where he was given an EEG. The results were normal, and they were told that Steve did not have brain damage. His doctor thought that a thyroid medicine would help him. His mother felt that it did no good. She would like to have gotten Steve into the Child Guidance clinic.

His school experience in the special class was not a good one, and he went to another school district that had a special class; here he learned fairly well. He went to junior high school in still another district and didn't learn there at all. He had a woman teacher with whom he didn't get along. He went to yet another district to high school, and it was there that he met the teacher who became a benefactor to him. Steve's mother said that he learned more and did better because he had a wonderful teacher who treated his students as young adults. The teacher balanced criticism with compliments and praise and was intersted in helping the students. The teacher recalls that it was probably Steve's first good school experience. He and Steve stayed in touch throughout the years.

Steve's teacher says that he was brighter than most of his students, but that he was stubborn and would "rag" on students less able than he. The teacher said that the school district that Steve was from was known for evaluating behavior problems low so that they could send the students to neighboring districts that had special classes. He thinks that that is what happened in Steve's case, because Steve had tastes above that of a retarded person, and he produced at the upper levels in his class. The teacher sometimes ran into Steve downtown at classical music concerts and gave Steve a ride home, when Steve had gotten there on the bus.

Steve returned to his own school district for his last years in high school. The major drawback at this school was Steve's teacher. She treated her students as if they were younger than they were. They had to walk in line when going to the library, while the regular students went

freely. His next teacher was not much better, commented only on things that were not good enough, and lacked a sense of humor. He pictured Steve as always being dependent. Steve's mother criticized the school for doing nothing to prepare Steve for a job and felt the school should have had a better vocational program. Steve liked shop classes, did well in them, and made a shelf for his mother that was as good, if not better, than those of the other students.

In spite of the teachers, Steve was eager to attend high school. He was learning at a faster rate and everything seemed to be coming more easily to him. He could read well, but math was still difficult. It took a long time to learn about money, but he eventually learned it well. At this age, he resented his family's helping him with his school work. "He thinks he knows and doesn't want to be told," his mother said. But, he did get along well with other students and knew a girl who was a very good friend. They had dinner together at one another's houses, attended church together, and went to the school dances or football games, and the movies together.

In contrast, when Steve was younger, he played by himself a lot because he couldn't catch a ball as well as the other children could; his coordination was not good, and the others chided him about it. His mother says he took a lot of hitting and didn't return it because she told him not to. He did play with one boy who was a year and a half younger and they seemed well matched. Steve tried cub scouts, but he got confused and it seemed to be too much when added to the difficulty he was having at school. His mother, looking back, was sorry that she didn't keep him in the scouts because he felt left out since his brother was a scout.

Steve's mother worked at helping the family understand Steve's problems. When Steve and his older brother were little, his brother would get impatient with Steve. But as his brother became old enough to understand that Steve had a problem, he made allowances for him. When Steve's little sister belittled him, his mother explained that Steve was a little slow. "I won't have her belittle him," his mother said emphatically in the 1959 interview. "She's asked not to point Steve out as different," his mother continued. Steve's father never had great patience with Steve, but he was ill and was not too involved with any of the children. Steve behaved better with his mother because she took more of an interest in him.

Steve grew up in a warm, stable atmosphere. However, Steve's stubborness was a problem. His mother was stricter than his father, and she spanked him frequently until he was five. But, she also believed that when the children were angry, they should express themselves, without being disrespectful. The family lived in the same neighborhood all of the time the children were growing up. The neighbors were close and got together for spaghetti dinners and fish fries. Steve's appearance was similar to the other children, and he was treated well. There was one little girl in the neighborhood who tormented Steve, but his mother called her down for it. Steve's grandmother was also an important part of his life until she died. Steve would go over and garden for her, and she would read Bible stories to him. Steve and his father built a lath house, and Steve had a little nursery of about two hundred potted plants. He did gardening on

Saturdays for family friends, and he was expected to do yard work at home. He cooked breakfast and lunch and did the dishes. He was exceptionally clean. His mother encouraged him to do things by himself. When he lost interest in his lath house, it remained neglected. She did not take care of it for him.

The family was close knit, and they took vacations together. Steve was close to his younger brother; they rode bikes and took walks together. His older brother seemed to be embarrassed by Steve when he was younger, but as they grew older, they began to enjoy each other more. His brothers have helped Steve a lot, and their examples have motivated him. They have conversations on topics familiar to Steve such as music and trips, so that Steve can contribute, too.

Steve's mother describes him as having been a happy child, a loving boy who was a tease. He liked to pretend that he was superior and sometimes gave his mother a friendly punch. Although he felt different from the other children, the others didn't treat him differently. When he was eighteen, he was six feet two inches tall. His mother remarked, "The way he's going now, he'll be just like anyone else. Not be noticed. He's made a lot of progress in the last year." However, Steve knew he was slower than the other children and he would say, "I wonder why I'm so slow." His mother said that he realized that he wasn't slow in some other ways. His judgment was good, and he was aware of what other children were doing. "He is just slow in learning; in other ways he's normal," she said. He would ask, "But I'm not dumb, am I?" His mother would reply, "Well, no, just do your best." She never considered him retarded, just slow. He enjoyed the same things that other boys enyoyed; he listened to records and watched TV.

Steve continued to make progress after he graduated from high school. With the help of his former teacher, he got a job in an ice cream parlor. Steve made delicious ice cream desserts and worked the cash register. When the ice cream parlor went out of business, the same teacher helped him get a job in the cafeteria at a local hospital. Steve also worked for a newpaper making telephone sales. He still has both jobs and is the paper's top salesman.

Steve almost lost his job at the hospital, and again his teacher helped him out. His teacher tells the following story: "I had this student who did quite well in school. He also lived in the city where I lived, and he was out of work. I had contact with the hospital and I found a position for him there. He had done quite well; he's a very attractive young man, good personality, and it had worked out, I thought, very well. The job was coming along; he enjoyed it, and they seemed to enjoy his work, and then I received a call that they were thinking of letting him go, and when I went in to talk to the people in personnel and his immediate supervisor, I found out that they had promoted him to a higher job, because he did have such a nice appearance. But this job involved too much responsibility, and he was at the point of quitting. Instead of trying to work it out, he was just going to leave, and so I talked to them about it and asked them if they had been pleased with the work he had done before. They said he had been the best employee they had had doing the work he had

been doing. And I suggested to them that they put him back on that job, taking him off the job that had too many decisions to make and too much responsibility. They did, and he's still working there. I think he's been there about twelve years now. He's doing quite well; he likes the work; they like him. I'm real pleased with him."

The incident that precipitated the phone call to Steve's former teacher involved ordering Steve to take quick action during an emergency. Steve was asked to get something from a closet quickly, and he froze. He eventually got the article, but he just threw it down. The job that he returned to involves very little interaction between Steve and anyone else. He knows what to do and he does it. He works in the cafeteria empting trash and keeping the napkins and silverware supplied. He works independently and responsibly.

Steve took the initiative in creating his own social life. He looked for friends at church. He had to go to several churches before he found a congregation that accepted him. At one church he attended, he remarked that no one ever invited him to their home or to go out for a coke. Steve was aware that he was excluded. His present church included him in their social life. He met his wife at church. She is physically as well as mentally handicapped. When they met, she was living on her own, working at a nearby junior college. Their church was expecially supportive. They offered classes for young couples about to be married and Steve and his bride-to-be went to them before they were married.

Steve and his wife had a beautiful formal wedding and reception in which both families participated. Steve's former teacher attended and recalled that everyone was happy about the marriage. Steve's mother was happy when he moved out on his own. It gave her a chance to be concerned with her own life. After Steve's father died, she provided for Steve until he was in his thirties and was married. Steve's wife's family was very happy also, and they are very supportive of the couple. Steve and his wife have their friends from work and church, and Steve still holds two jobs, so they are busy. They have been married more than five years now.

Life History of Donald (Outlier Doing Worse Than Predicted)

Donald's life history is drawn from interviews with his mother in 1959, 1983, and 1984, his counselors and social workers, a teacher who worked closely with him during elementary school, and the researchers' observations from viewing an interview for the local TV news program. His mother has had a cancer operation and said she didn't want him disturbed. The fact was that he had gotten into trouble and was about to be excluded from the place where he had been living.

Donald's mother had four children, each four years apart. Donald was the second child born. He had an older brother and a younger sister and brother.

From the time that Donald's mother was six month pregnant with Donald, she had diarrhea and couldn't keep food in her stomach. She thought that she would lose him. Near the end of her pregnancy, she went to the hospital because she started hemorrhaging. Donald was born full term, but he weighed only five pounds. Donald's mother heard the doctor pleading for to Donald to cry, yet the doctor told her that it was a normal birth. Donald was her second child, and she felt that it was not a normal birth. The doctor used forceps, and she thought that he injured Donald. His mother said, "From the time he was born, I knew there was something wrong. He had this funny look. His head had a bump in the back. I wanted him to stay in the hospital. I said I'd go home, but they said,"No." He slept all of the time. He wasn't eating. He didn't sit up or turn around when he was supposed to and they said, 'Oh, that's nothing.' They said I was imagining things. His bottle was like a pacifier. At a year old, he was not taking anything off a spoon. I was afraid he wouldn't eat anything so I let him keep the bottle. When he was two to two and a half years old, he started fainting. I took him to White Memorial Hospital and they sent me from clinic to clinic. I gave up. They said I'd have to put him away. He just started walking at two and a half, and he stopped fainting. Donald didn't talk yet. I didn't think that he was retarded or anything. I began to work with him to make him talk. He would point and I would know what he wanted and give it to him. The doctor said, 'Don't give him everything he wants. You have to make him talk or else he won't try. He's getting everything he needs.' He didn't say 'mama' but he started to talk by saying nursery rhymes he had memorized. I didn't see how anyone could say a child of two was mentally retarded yet. He hadn't had a chance yet. I felt angry and shocked because I didn't think there was anything mentally wrong with him. I just thought he was slow, talked later, walked later. When he was two, he was like a one year old."

His mother continued the interview, "I knew he wasn't ready for kindergarten. He was never a good looking child, gawky. In kindergarten, he wouldn't stay. He would wander off. The school psychologist said that Donald couldn't stay, but she didn't think he was eligible for a physically handicapped program. She told me about special classes in another district. I was ready to sell my house and move. He needed school, but he was never happy. We moved and he went to a special school. He was really trying. He loved it."

The family moved, and Donald went to another school. The teacher made a spectacle of Donald in front of the whole class for something he had done. His mother said that she had no trouble with Donald at home and she didn't understand what the problem was at school. Then the principal of the school called and said that she thought that Donald might have T.B. and arranged a medical exclusion for Donald. His mother took him to Children's Hospital and had chest X-rays taken. The hospital sent a letter to the principal saying Donald was fine. The principal kept saying that she had not received the letter, and she kept Donald out of school for three months. By that time, it was June and school was out for the summer. In September, school started, and the principal started calling Donald's mother again. His mother took Donald back to the special school and she says that they straightened Donald out.

One good thing came out of the ordeal that the principal put Donald's mother through: she found a doctor at Children's Hospital who took an interest in Donald. The doctor thought that there might be pressure somewhere on his brain. She also said that Donald might have cerebral palsy. Donald's mother was in a quandry from the time that Donald was two and a half until he was six. She said, "I read everything I could get my hands on." She read about children who were small for their age because she wanted to find out what was wrong. She lost weight and was afraid that if she left Donald, something would happen to him. She felt that no one could take care of Donald but herself. Finally, her own doctor recommended that she go to work.

When she became pregnant with her third child, she worried that something would be wrong with that child, too. She had always felt guilty about Donald, asking herself, "What did I do?" Her next two children were born healthy.

Donald's mother sometimes contradicted herself when she talked about Donald's handicap. She said of Donald, "He had a head shaped like a football. His eye turned in, and he wore glasses between the ages of three and four which seemed to correct it. He had a hernia operation when he was four years old. He had had the hernia when he was tiny, and no one would operate on him. The doctors claimed there was something wrong with his central nervous system. They tried new tranquilizers that had the opposite effect on him."

Yet, with all of Donald's problems, his mother protests," Donald doesn't know that he is sick. In my home no one knows something is wrong. He is the same. If I say something is wrong, then Donald would have an excuse not to do anything." She admitted that Donald did know that his younger sister could read better than he. Donald's mother always read to Donald because she didn't want him to feel bad. When asked how her parents felt about Donald, Donald's mother said that they didn't know about Donald, and yet in another part of the interview, she said that her father said that Donald shouldn't be kept at home. This was when Donald was thirteen. Donald's mother said that her mother-in-law knew something was wrong but didn't know what it was. "I don't go out of my way to tell her anything unless she asks. She doesn't accept things not perfect," Donald's mother explained.

At another time, Donald's mother said, "I tried to make no difference, but there is a difference anyway. Your home life is different. Your children become more kind. My oldest son knows something is wrong with his brother, and he is very considerate of anyone with a handicap or that needs help. The younger ones, as far as they know, there's nothing wrong with Donald." But, a teacher at Donald's school said that since his sister went to the same school as Donald that she must have seen the other children taunt Donald and have known that he was seen by others as different. The teacher felt that it was difficult for Donald's mother to admit to others that Donald was mentally retarded. His mother did say that it was a shock to her because there was never anything like mental retardation in the family. She says in the same sentence that she accepts that he is mentally retarded, and, although someone else might realize that there is something different about Donald, no one else would know that there was something wrong. One would just think he was an extrovert. In all fairness to his mother, Donald is very articulate and if he were only heard and not seen, one might think there was nothing wrong for a short period of time.

Donald's mother had two experiences concerning mental retardation that left a strong impression. When she was little, she visited an insane asylum and this is what she pictured when the doctors suggested that she "put Donald away." She vowed that he would never be institutionalized. "Retaradation does not mean insanity" she said emphatically. The second experience was with a relative who had a child who had had a high fever and was left permanently damaged. The relative doesn't bring the child out if people are visiting. Donald's mother wouldn't treat Donald that way. "He sits at the table and eats with us just as anybody else does," she says.

Donald always had trouble in school. After a year at the special school, Donald went to a special class in a regular school. When he entered that school, the teachers of the special classes had their usual meeting to see in which class he should be placed. One of the teachers at the conference commented, "We had a difficult time deciding which class to put him in. He was a misfit." In retrospect, his mother felt that it was a mistake to put him in a regular school, even in a special class. "It is better not to mix handicapped children with normal children," she thought. Donald was teased by the children in the regular classes. He would come in with his shirt torn and the children would have taken Donald's nickel or dime. Donald would be upset because he was not supposed to get dirty, and he had been told how much change he was supposed to bring home from his milk money. One teacher said that if he thought he was supposed to have a nickel in change, it was easier to give him the nickel because he would keep repeating, "My mother says I must bring home a nickel." At first, he brought his own milk, but he spilled it so many times that he had to buy his milk. "He was so clean he squeaked," the teacher went on to say. He would have to be watched on the playground, for he would disappear and he would be found in the bathroom washing his hands. He would have been washing them for twenty minutes.

Donald did not do much better with the neighborhood children. He did not want to go out and play; he told his mother that no one liked him. She thought that he was imagining that no one liked him, but one day she overheard a converstation. Donald said ,"Hi." to some children. The

children said, "Here comes Donald. Go on home." One mother told her children that Donald was a mental case and they said, "Let's not play with Donald." He did play with two or three little boys who knew that he went to a special training class and they accepted him and knew what his problems were, his mother said. She had told them that Donald had coordination difficulties, that he couldn't write. "I explain it," she said.

Donald's mother was quite concerned with Donald's not writing. She mentioned it in many contexts. She said that her older son had gotten Donald to write. "He writes, 'I am a good boy.' He writes backwards. Why he does it I don't know," she declared. She thought she might get Donald a tutor. That might make him want to write. "If it was with a stranger he might write," she said. When she was discussing Donald's school, when he was thirteen, she said, "He's not doing enough in school. He insists on writing backwards. I don't know why he won't write; I try to get him to sit down and write and he won't do it." Again, when she was telling about Donald and his father, she said, "Donald wants very much for his father to like him. He'll do anything he asks him to, even his writing which he doesn't like to do. Donald will do it for him."

As Donald's mother describes her family and their treatment of Donald, the difficulty that each member had coping with Donald's problems becomes apparent. She said that Donald's retardation was hard for her husband to accept. He took jobs away from home to escape and then felt guilty. She said that Donald tried harder with his father. No matter how emotionally upset he might be, he didn't let it show with his father. Donald's mother said that Donald's father was more high strung than she, and he felt she was too lenient with Donald. She perceives Donald as not usually doing anything wrong. She didn't feel that she had to spank him because she could get him to do anything by just talking to him. Once in a while, Donald would go to the store which he was not supposed to do and his mother would say, "You're not going to do that anymore are you?" and Donald would say, "Can I ever?" "When you're older," his mother would reply. At age thirteen, Donald was to stay within a three block area, because he had been missing a couple of times. Donald would come home from school and blow up. His doctor had warned his mother that Donald might have tantrums so she just let him blow off steam. When he got mad he said everything he had ever heard, and there was no use stopping him; when he was finished, he was all right. His mother took pills to stay calm. Donald was nervous and he talked constantly. If there were people at the house, his mother would say, "Older people don't do that," and he would be quiet until he forgot again. The tactic that worked the best was to compliment Donald and ask him to do what you wanted him to. He would do it. He took a lot of his mother's time and the other children thought it was unfair, but his mother decided that he needed it so he was going to get it.

Donald's mother described Donald at age thirteen as an affectionate, good boy. She expected him to keep his room clean, wash his face, and brush his teeth, but, she said that she bathed him. He took tranquilizers because he couldn't control his motions. He used a spoon and a fork but "I don't give him a knife," she said. "He's very irresponsible with money," she continued. He still wet the bed if he was upset. She said that he

thought nothing of getting undressed and walking around the house. She admonished him that he was a big boy and must keep his clothes on. She also said that he hadn't asked anything about sex yet. She said,"His mind doesn't run that way. He's like a nine year old. His father should tell him when he is older."

His teacher, however, complained about Donald at school. She said that he would look under little girls' dresses. When the teachers realized what he was doing, he was required to be in his chair or, if he were sitting on the floor, would have to face the teacher. She also told of an incident that occurred when Donald was twelve involving his emerging sexuality. One morning, he woke up with an erection. He was frightened; he thought something was terribly wrong with him, and he didn't want to go to school. His mother was upset also and called the doctor. Donald did not return to school for two weeks to a month. When it came time for Donald to go to junior high, the teachers didn't think he was a candidate to go on. They felt that he had an unhealthy curiosity about sex. The normal functioning of his body had not been explained to him. They felt that Donald would have to be watched, and they considered recommending custodial care for him, but they never came to a decision on the issue because his behavior fluctuated. Most of the time he was listless, but sometimes he was hyperactive. They all agreed that he was a handful. Donald's mother said that the teacher didn't want him in school so he never went to high school. His teachers said that she withdrew him on her own.

A teacher at his school also described Donald at age thirteen. She said he was very polite and never showed a temper at school. He was slight of build, and when he began to grow, he became even more awkward. His feet were so big, he couldn't keep them straight. His parents made him wear high top shoes until his teacher suggested that he wear regular shoes. He was very proud of his new shoes. If it rained, he was dressed in all possible rain gear, and he insisted on wearing it all because his mother would pick him up and expect him to have it on. His teacher thought that his mother expected too much of Donald, pushed him too hard. She observed that his parents did not spend much time with him, and that he did not seem to have the support from his brothers and sister that some of the other handicapped children had. She worried about Donald because she couldn't tell how much of his learning difficulty was from a handicap and how much might be from emotional problems. He spoke very well. He was very diplomatic with adults, and he kissed the girls' hands as if he were Sir Galahad, but the teacher could spend all morning with him on 1 + 2 = 3 and not make any progress. When Donald felt expecially restless at school, his teacher would let him look at magazines, an activity he enjoyed very much.

Donald's mother, talking about school, said that she thought that he was in the right placement, and she thought his teachers were patient with him, but she felt that he was not getting what he should. "He's not doing enough in school," she said. She thought his teacher was good; the teacher had let a girl help him in class, and he had liked that. Donald's mother visited the school once a month and stayed in the class to observe. The teachers commented that she would often bring them presents. They felt that she had had such a hard time keeping him in a school that she tried to be extra nice so that he would not be excluded from school. When she came

for a parent-teacher conference, however, and the teacher told her of Donald's problems, she would just wring her hands, not knowing what to do.

Donald's mother was aware that Donald needed to be more independent. If he asked her to do something for him that she felt he could do by himself she would help him and then say, "Now you try it." She said that he had become more independent since she had started working. "He has learned to do things he wouldn't have otherwise."

Donald didn't finish school, and his mother wanted him to continue to learn. When Donald was nineteen, she learned about a method to work with brain damaged children on the Mike Douglas show. It was called the Delecato method. She took him to a doctor who used the method. The method had the child go through stages of development that he had not completed such as crawling. The parents were taught how to work with their children. Donald's mother worked with him at home for eight hours a day for a year, and she saw results. Donald learned to swim and his coordination imporved. His involuntary movements went away. He was able to bowl and play baseball. His concentration improved and he went from not knowing his alphabet to third grade reading level. He has not retained his reading ability, but the involuntary movements have not recurred according to his workshop counselor and the researchers observations of his video tape interview.

When he reached adulthood, Donald went to live in a group home and to work in a workshop. He didn't work, so his parents changed him to a different group home and workshop. His second placement didn't work either, and they tried still another place. His social worker at the the third placement said that when he first came to this placement, they couldn't get him to shower or change his clothes, but he settled down and they thought he might be a good candidate for training for independent living. However, both the woman who worked with Donald at the workshop and his social worker were afraid that his parents might prevent Donald from being more independent. They felt that his parents were loving, but that they were over involved. In the past his parents had presented barriers to effective programs with Donald. His parents were pleased that Donald was finally peaceful.

Donald's verbal ability gave him a special place at the workshop. He led tours at open house and was in all of the pictures with the celebrities who visited the workshop, and was even interviewed on the local TV news.

Donald's progress at the workshop was halted when he got into some trouble that was serious enough to involve the police. His counselor said that he was a sexually troubled young man. A staff meeting was held to discuss the matter and his parents were invited, but they chose not to attend. His workshop counselor argued on Donald's behalf because she felt that the group home provided no sexual outlet for the men who lived there. They were even watched with binoculars to prevent them from engaging in any sexual activity. The board of directors, however, decided that Donald should not be allowed to stay at the group home and workshop. Donald returned home.

Life History of Susan (Outlier Doing Worse Than Predicted)

Susan's mother fell and had some spotting when she was pregnant with Susan, and Susan was born three weeks prematurely. The doctor was supposed to be at a dinner a few minutes drive from the hospital, so he checked with the nurses in the labor room to see how Susan's mother was coming along. The nurses ignored Susan's mother when she said that the baby was coming soon and told the doctor to proceed to the dinner. Susan's mother, who had three boys at home ages two, three, and five, knew that she was about to deliver. When the baby started to come, the nurses held her legs together and gave her ether until the doctor arrived. He came fifteen to twenty minutes later, and Susan's mother thinks this tactic caused Susan's handicap. Three years later, Susan's mother had another baby girl.

Susan had two serious illnesses when she was very young. At a year old, she came down with the chicken pox, but didn't break out, and her fever soared. At a year and a half she repeated the scenario with the measles. This time she had convulsions with the high fever. She had been developing normally before the illnesses and there was no apparent change after them. She had begun to say mama, daddy, and Jackie at the normal time, but she seemed to go no further in her language development. Her mother questioned, "A normal child who don't talk; What do you do?" What she did was take Susan to the doctor. He told her not to fret so much because Susan appeared normal.

When Susan was two, her mother took her to another doctor and he said that she had pressure on her brain. He gave Susan chiropractic-like treatments and she became noticeably more alert. At three and a half, Susan had her tonsils out. By age four, she still had not started talking, and her mother took her to another doctor. He examinined Susan and said that she was normal; others were probably just talking for her. Susan finally started talking, but she had a language of her own that only the little girl across the street could interpret. Susan grew very frustrated when she tried to communicate and her mother didn't know what she was saying. Susan sounded like a deaf child.

Susan's mother wondered what to do when it was time for Susan to begin school. The only place that Susan could go would be the state school for the mentally handicapped. The doctor told her about special classes for children like Susan in California, and she and her husband left their friends, family, and job in the Midwest to move to California to provide Susan with an education. Susan's first school experience was a good one, until her class got a new teacher; then she stopped improving and had to repeat kindergarten.

During the spring semester of her second year in kindergarten, Susan was evaluated by the school psychologist. Susan was shy and did not do well. The Friday before Easter vacation, the school psychologist telephoned Susan's mother and told her that Susan should be placed in a school for the trainably mentally retarded. Up until this time, Susan's parents thought that she just had a speech difficulty. Susan's mother recalls, "I was so upset. It's hard to accept, to be told that she can't learn." Susan's mother couldn't talk to anyone from the school because it

was Easter vacation. At the same time, another one of her children required an operation. Problems seemed to be mounting up, and she had a nervous break down. She had no energy and couldn't seem to do anything. She stayed in her room and slept.

When vacation was over, and Susan's teacher learned of the school psychologist's decision, she was angry. The teacher said that Susan gave 105%, and she felt Susan should stay at the school in the special training program. Susan's mother talked with the principal, telling him that she wouldn't send Susan to the school for the trainably mentally retarded. The principal had a handicapped child himself, and he thought that parents knew their children better than school personnel. He allowed Susan to remain at that school.

Susan had two major learning disabilities: poor memory and poor auditory perception. She asked intelligent questions, but because of her poor memory and her difficulty understanding what was said, she would ask the same question the next day. The speech teacher held a summer workshop, without pay, to train parents to work with their children. Susan's mother worked with Susan to improve her memory. She would put three items down and take one away and ask Susan which one was gone. She would repeat the exercise using five items. When Susan began to read, and she could see the words, her speech improved. There were clues to point to Susan's auditory perception problem, e.g., a language of her own and deaf-like speech which improved when she saw the words, but an auditory perception disability was not mentioned in the school psychologist's report until she was seventeen, and then no plan for remediation was suggested. On the contrary, a previous school psychologist's report suggested that she improve her social skills by joining in discussion groups.

Susan's academic progress took a great deal of patience on the teacher's part. It took Susan a long time to learn something, but once she learned it, she didn't forget it. Susan said,"I studied and when the other students were finished with a test, they said,'Aren't you finished yet?' I studied and got 100% on a test." She wrote upside down and backwards. She was a quiet child in class, and if the teacher became busy with other students, Susan would quietly put her head down and go to sleep. She had frequent colds and was absent a lot. The teacher never knew if Susan's mother was keeping her home unnecessarily, or if she were protecting Susan's delicate health. Susan's absences were frustrating to the teacher because it was hard to make progress when the lessons were interrupted. Susan's teacher remembers her as being sweet, easily hurt, willful at times, but always beautifully dressed.

Susan's mother still sought medical help for Susan. Susan's EEG showed a normal brain wave pattern. When Susan was nine, the doctor prescribed medicine sometimes given to older people to improve their memory. However, Susan developed an allergy to it, and it also made her nervous, so her mother discontinued the medication.

Patience was not one of Susan's mother's natural qualities, but she certainly developed it. It took her two years to teach Susan to do a cross stitch in embroidery. Susan would be able to do it one day, but by the

next day she had forgotten it. Her mother also taught her to perform household chores which helped Susan a great deal in school, since Susan's teacher taught her class practical living skills which included preparing meals. She always gave Susan the task of setting the table because Susan knew how to do it and did it responsibly. Susan remembers this assignment with a great deal of pride.

Susan has happy childhood memories of her brothers and sister. She says, " When we were little, my brother used to cover me up with sand up to my neck. Then he would tell me to move. I could only move my toes. I would cover him up. We'd go in the ocean and wash all of the sand off. When we were all covered with sand, it felt like cool wetness all over your body." She goes on, "Oh, it was great having my sister's friends. They was nice to me. We went over to their house and played, or they came over to our house and played - rollerskating sometimes." Susan remembers when her brother would help her with her school work, "My brother would see me struggling on a test, and then he'd say, 'Here, I'll show you how to do it' and I got it right. I felt happy and he was happy too, cause he said at least I tried. Don't give up--try, try, try. And that was great." Her brothers helped her in other ways too. She says, "The neighbor kids down the street used to call me names, and my brothers would go over and fight my battles."

Susan's mother was aware of her being teased, also. She tells the following story: "I've always been very open with everything. I felt it was important to face the real world and Susan had had an experience when somebody had called her retarded and she came in the house crying and I told her, I said, 'Well, Susan, retarded's nothing terrible.' I took her to the sink and turned the water on, and I held it back and I said, 'Now I've retarded the water, it's slower than it was when it was full open,' and I said, 'We all of us have things that we're retarded in. I can't play the piano, so in that area I'm retarded,' and I said, 'There are things you can't do and so you're retarded. It's not a bad word; it's nothing terrible.' and so she's always said, 'Oh, it just means that you're slow.' Too many people put derogatory things upon retarded. When I would say to someone, 'She's retarded,' they'd say, 'Oh, she's not,' and I'd say, 'But she is, and if you expect things of her that she can't do, you're going to frustrate her.' She needs to know that there are her limitations. We all have limitations in one field or another; we can't all do everything."

The philosophy that has guided Susan's mother in raising Susan is suggested in the above story and more clearly articulated by her in the following statement: "I think it's important to just accept the child as any other child and try to find their assets and work with those, praise those, make them have a feeling of self-worth as much as you can, and help them with the things that they are able to do, and if you find they really can't do something, then try to avoid it if you can. You know, not have to make them feel dumb or worthless or whatever they might feel from not achieving something."

Included in Susan's mother's philosophy is a method for handling guilt that a parent might feel as he loses patience with his handicapped child and a statement about how it feels to have a handicapped child. She says,

"I think what causes a lot of problems in the children is the parents have to accept them just the way they are, and they have to love them, just the way they are; they can't change that, because that's what was given to them to accept and love and there're many more rewards than there are things that would upset you because they're so child-like even after they grow up; they're so open, and they give you a lot more than they ever take. If you just leave yourself open enough to accept it and take it, because they are usually more loving than the other children are, more open with it. If you aren't the most patient person in the world and you get upset with them, don't blame yourself if your human. Just try to pick up the pieces and go on, because if you blame yourself, pretty soon you'll end up with so much guilt inside yourself that you'll take it out on the child, and that's not right. It's not easy, that's for sure, because there's always something new comes up and you have to learn to handle that, but I find that with my kids that are married. I guess with the other children, you're able to kind of divorce yourself from it and say, 'Well, that's their problem not mine.' Where Susan's problems are always mine and always will be, because she needs that backup support that the other children are able to take care of themselves. I think the hardest thing would be times when you would be watching the children playing and it just doesn't seem fair. I think Susan looks fairly normal and yet some would get (crying)...it was hard to think to yourself, 'Why? She's not normal, you know.' I think that was the heartache, and you learn to deal with it. I don't know when, I'm still (laughing), but it is hard. I think seeing them kind of left out, but not with her family, but with others, that's very hard to deal with."

Susan has fond memories of elementary school. She tells about the time when she and some other girls performed a lip sync of the Andrews Sisters. "Knowing me, I don't know how I did it. We played a record and just pretended to sing. The kids liked it. It was just the kids in the class, but they liked us." She didn't attend the ninth grade graduation because she was wearing an eyepatch, but she went to the restaurant afterwards. Her teachers still remembers the blue dress Susan wore and how nice she looked. She was not overweight in those days, and she was attractive. When she took the bus to school, her mother waited with her at the bus stop to make sure she was not harrassed or molested.

High school was not a pleasant experience for Susan. Puberty was difficult, and she had terrible menstrual periods. In addition, she had a male teacher who was unsympathetic to her problems. Susan said, "The red haired lady teacher wasn't so bad, but he was. I passed out over there. The nurse said to stay home monthly. He said that I could graduate with a certificate, but it wasn't good for me. I was bleeding too much. I used two Kotex. The doctor said to take me out of school. The teacher didn't like that . His face turned real red. He's the Red Baron"

While in high school, Susan worked in the school cafeteria and the cafeteria manager praised her ability to perform household chores. She also went to work at the Goodwill workshop. Here again, she was embarrassed by those in charge and so she quit. Susan's mother encouraged more practical learning skills. She said, "Oh, I think functioning in society is more important than learning who discovered America, and I tried

often to get that through. I never really succeeded. I had tried one time to get the kids a cash register so they could teach them about money, and I thought it would be important for them to learn how to get on a bus and how to go some place. I think they are more readily able to learn by doing things like that, but there were so many parents there who were saying, 'My child's gonna catch up here,' and they wanted them to learn history and that kind of stuff. I think it's important to teach them history, but I think it is far more important to teach them just how to function in society, how to go out to a store and know how to buy things and how to utilize money and what money is. I had an awful time teaching Susan the difference in money."

Susan had two good friends in high school. One moved to North Carolina, and Susan still writes to her. The last time she was in town, however, she and Susan were supposed to go to lunch and her friend got too busy, and Susan didn't get to see her. Her other friend, Marie, and Susan had a fight, and only recently have they recontacted each other. Susan and Marie were best friends. Marie stood up for Susan when their high school teacher implied that Susan was truant, and she reported to Susan all that he had said. Susan and Marie talked to each other and shared secrets. Marie took Susan on blind dates. Marie asked Susan what she did with her boy friend on their dates. Susan had only kissed her boy friends and she felt that was none of Marie's business. Marie got mad at Susan and said that Susan had to apologize to her. Susan said, "It was her fault. I don't have to apologize, because I didn't start it. I sure miss Marie." Susan recently took a chance and sent Marie a card. Marie called and they are friends again, after many years of separation. They don't see each other as often as they used to, however.

Marie and Susan had many adventures together. One time, when they were going shopping, they got on the wrong bus. They transposed the number 74 and got on the 47 bus. When no one was left on the bus, they asked the bus driver where they were. They were both crying by this time. The bus driver asked them where they lived, and he helped them get back to their neighborhood. They called Marie's mother to come to get them.

There were two boys that Susan dated; one drove and one didn't. Susan tells about two adventures with Nick and the car. "He had a dune buggy and we got stuck on the freeway...I go, 'Pull over, they're honking the horn at you.' 'I know, I know,' he just got upset. I made him get over, and we called my dad, and he came and got us. I was so scared."

"Another time, he was taking Marie home, and we were clear out to another town, and he said 'I know where we are' and Marie was getting upset, and her boy friend was getting upset too, and we had to calm down because he was almost losing his composure. And we both just shut up and we just went , 'All right, we'll let you...' but we finally got home, which I was glad."

Susan still speaks wistfully of Nick, "His folks are rich and give him anything he wants. Once I was over at Nick's house, and his mother said I was saying, 'Touch me, kiss me.' It was Nick who was talking, but she thought it was me. She called my mother. Mother told her that Nick had

come over and asked her and dad if he could marry me. Nick made a rubbing on my arm right in front of my mom and dad. He pulled me down and I wouldn't let him. Mom said he might be the type that would beat me, so she didn't want me to marry him."

Susan also remembers, "Once we all went to Knott's Berry Farm, and I was the only one that had money for tickets. Marie and her boy friend and Nick said they'd pay me back. I kept asking, and he finally did. I didn't tell mom. She asked, 'What did you do with your money?' He's probably married by now."

Susan does not sound as if she misses her other boy friend, Bert, as much as she does Nick. Susan tells about Bert: "Bert lives in one of those places for people like me in Arizona. He wanted me to come and live there too, but they find work for you to do, and I can't work. I could never have a job. My mom and dad were supposed to pick Bert and me up from Knotts Berry Farm once when we went, and Bert got mad because he wanted to stay til two in the morning. Mom and dad couldn't pick us up then, and buses would have stopped running. Mom could tell Bert was mad. They took me home first, and she said he just slammed the car door and didn't thank them for picking him up. Bert and I would meet at the shopping center and walk around. He wanted me to go to his place to swim once but mom wouldn't let me go alone. Bert wanted to marry me right away. I don't know why. Maybe it's my good looks."

Susan's teacher says that Susan's mother was worried about Susan's having boy friends because she didn't want Susan to get pregnant. She knew that she would have to raise the grandchild. Since Susan had a histerectomy because of hemorrhaging during her periods, her mother was relieved of that worry.

Susan's mother talks about Susan's having boy friends, "Susan is very highly motivated morally. She knows right from wrong, and we had started out when she was young with the school psychologist who said, when I asked her,'How do I go about teaching her about sex? I know that's the strongest drive that any human being has and it's bound to be there with her too.' So she said, 'Well the best way is to give them cats and let them have kittens, let her watch, explain it to her and the whole thing.' So we got three mother cats and they all had kittens within just a few weeks, and I ended up with twelve cats. Susan didn't want to part with any of them. But she's learned a great deal about how babies are born. Of course, she didn't see the conception of it, but I had explained that to her. Then when she had dates, well, the one boy she quit going with him because he ran stop signs, and she knew that was wrong and she said, 'He's gonna get us killed.' And then the other one, he got a little friendly with her and he was really kind of funny about it because they sat on the davenport right in front of me and he was, had his arm around her and he was kinda trying to get a little fresh with her, and she would pull his arm around and hold his hand and then he'd pinch her and she just got really frustrated. He had taken her some place, and they was out on the freeway, and his car was acting up, and she told him to pull over in the outer lane. Then she finally got him to do that, and then it stopped, and they had to walk off of the freeway, and she said, 'I'll never go with him again.'"

Susan's mother continued on the topic of Susan's boy friends, "The first thing these boys said was,' Let's get married.' And she said, 'Oh, if that's what you want to do.' And I'm saying, 'Now Susan, think about it. Would you like to spend the rest of your life with this person?' and she thought about it and she decided that really wasn't for her. In her other brothers and sisters, she sees the problems with learning to live with another person. Marriage is not all roses. I think, I'm sure within her heart she would like to have somebody to care just for her only, but I don't think just anybody. I think it would have to be somebody who really cared for her, and that hasn't happened. It probably won't, and I think she realizes it. So I think it's one reason she enjoys the TV; she gets her fantasies out with TV, and then she's enjoyed all of her nieces and nephews. We have sixteen grandchildren, so she's had a lot of babies she could cuddle and love and they all seem to love her. When they get a little older, sometimes, they get a little distant with her, but when they're little they all of them are sweet to her.

Susan's family is very close. A brother or sister is continually dropping in, usually with one or more children who climb on Susan's lap. Susan's mother claims that Susan has less patience with the children as she grows older. When Susan and her brothers and sister were younger, the whole family went on trips together. Susan's mother has never felt the need to get away from the children. She has fun with her children. The family traveled to Washington, D.C. and many other places in the United States. Susan's mother thinks that travel helps her children to learn. When the Olympic Games were in Susan's area, the whole family got together to watch the Olympic torch pass by their house. Susan was thrilled, "I got kissed. A man in the group accompanying the torch bearer, that is there in case he falls, they catch the torch, asked me if he could have my sign. I didn't know what to say so my sister's husband said, 'Yes.' and the guy hugged and kissed me. My sister made the sign. I didn't have time to help her."

Susan does a lot with her sister. Her sister teaches her new embroidery stitches and helps her decorate the house at holidays. She also takes Susan to swap meets, Disneyland, and Knotts Berry Farm.

Susan's relationship with one of her brothers is mixed. He has confided in his mother that he is uncomfortable around Susan. Susan's mother thinks that it is his wife who is more uncomfortable than he. Susan said that he had hurt her. He and his wife had invited Susan's sister and her family over for a picnic and a swim and didn't invite Susan. Susan saw all of the picnic things in the trunk of their car and heard her brother's wife ask one of the kids if she would have to fix a hot dog for her. Susan knew that something was going on, and her sister said that she had hoped that her brother and his wife would say something to Susan, but they didn't. "I was really hurt," Susan said. " He told mom that he doesn't know me very well, and he's uneasy around me. I went to babysit for them while they were looking for a house, and they said they would pay me, but they never did. I didn't tell mom, or she would get mad. They didn't mind having me around then." Yet this same brother helped her get a computer so she could improve her reading and math when he noticed that she could work with the one he had at home and he is the brother who used to help her with her homework.

Another brother took Susan to her tenth class reunion. She was dressed up and so was he. Their picture decorates the den.

Susan's life is much calmer than it was when she was in her twenties and was dating. Her father is retired and he and her mother are at home most of the time. Her father used to work evenings and her mother helped her brother out at his pizza parlor. At that time, Susan had a routine. She would get up and shower. Her mother would have left a shopping list and Susan would walk to the market. After her father got up, she would vacuum the house. When he left, she would walk to the nearby shopping center. On her way home she would stop at Carl's Junior. Her mother would get home around six or so, and they would eat dinner around eight. If Susan's mother did not bring pizza home, they would have a Weight Watchers TV dinner. They would watch TV until Susan's dad came home. Sometimes they stayed up later, and all three of them watched something that they had taped on their VCR. Susan didn't mention watching any TV serials regularly, but when she talked with the mother of a friend, they both knew the intricate plots of the most popular day time serials. In fact, Susan was more accurate in understanding what was happening to whom than was her friend's mother. Now that both parents are home more, Susan is leading a less active life; she has gained a lot of weight. She was quite heavy before, but now she is even heavier.

In addition to her mother and father, Susan's household consists of two dogs, a bird, and Susan's cat. The dogs and bird each had been rescued from the street. Susan got her cat from a neighbor who was moving. Since the cat was pregnant, no one else would take it. Susan was thrilled. She was home with her father when the the first kitten was born, but he had to go to work and told Susan to call her mother at the pizza parlor. Susan called her mom telling her that the cat was screaming. Her mom said that some cats were just screamers, and there was nothing she could do. Susan helped her cat by gently easing the kittens out as she had seen her mother do with their other cats. Susan said, "There were a lot of afterbirths. I'm glad we're not cats." When the kittens were older, Susan's mom gave them to the pet store in the shopping mall to sell. Susan went to visit them every day. "They recognized me and were glad to se me," she said. Susan's mother said that Susan cried each time the pet store sold a cat.

Susan's health has not been good lately. She has abdominal pains that have not yet been diagnosed. Her health prevents her from being as active as she would like. Except for health problems and a few social events such as a a weding or a lunch at a restaurant, Susan' life is relatively uneventful just now.

Susan Talks About Herself

There were a few topics that Susan mentioned almost every time she saw the participant-observer: helping her teacher in elementary school, being embarassed in front of others, her boy friends, and her needle work.

Helping her elementary school teacher has been a source of pride for Susan. She says, "She was my teacher and she would ask someone to help her

to set the table, and I always got the job and made the other kids, like they used to call me teacher's pet, but I didn't think that way, and I did a nice job. So she would try someone else, but they always got the silverware mixed up, and I always had it right. She showed us how to set it for special occasions and like salad forks and dessert spoons go a different way, which I didn't know until she showed - she only had to show it to me once and if I watched I knew how, but I got it right. I felt real good inside. She would let me go, like taking important notes to some other teacher or go get paper, you know, like colored paper and wrtiting paper and pencils at the office."

Susan was embarrassed by her high school teacher in front of the class and by the instructor at the Goodwill workshop in front of the other workers. She has not forgotten either incident. She describes the incident with her teacher, "Like if I was sick he would tell the kids, 'Well, is Susan faking, or is she really sick?' and that made me mad. I had a girl friend who told me things about him saying to the class, 'Well is she playing hooky?' and I didn't like that very well. So I used to call him Red Baron. He got real, real red in the face. I must have crushed his ego (laughs). Everybody'd go 'Yeah, rah-rah, Susan.' Once I asked him if I could go to the restroom, and he said yes, but come back. But I had problems going and I hurried back because he said not to stay too long, and they had problems with people going to the rest room and smoking, and I don't do that. So he thought I was taking too long, so I hurried back because I couldn't go anyway. So I came back, and I had my hand up again, and I said, 'I gotta go to the bathroom,' so he didn't say anything, well he did say, 'You was at the restroom.' So everybody said, 'Yeah, what did you do?' and I just got up and said goodbye, I'm leaving. I just went and I got in the restroom and I knew that someone came out and I was in there alone, and I hit my head and when I came to, someone was asking me, 'Are you all right, Susan?' and it was one of my class kids and told me that the teacher sent her to look for me, and when I heard her calling my name, I didn't see anybody; I couldn't see, and I hit my head, and the doctor said that could happen again, and he said it would be best to take her out of school because she could hurt herself real bad the next time if nobody was there."

Susan tells about working at Goodwill, "I had a little problem there and I folded clothes real nice and straight that people would mess up when they were looking or toys or stuff like that or dusting, and the head people changed everybody; everybody had to be changed over to a different working area, and I said, 'Okay, I'll give it a try.' And everybody hated to see me leave the Goodwill store, and they was in tears because they wasn't gonna see me - well, they would see me in the plant, in the building, but not as a working person. And they tried to get me, like, I guess you call it, a boss over ya, tried to do something so I could stay there, and they said no, so they changed me to working at a plant counting nuts and bolts, and she [the instructor] told me how many, so I was counting in my head and thinking, and here she is talking, and I lost count, and she said it was too many and yelled at me, scolded at me in front of a lot of people, and I didn't care for that, and I got so darn mad, I stamped out of there and went right to the restroom and stayed there all day until it was time to go home. They tried to look for me, well,

they got Marie to come and talk to me, calm me down, because I wouldn't listen to anybody else. I was in tears, I couldn't stop. But they said I didn't have to do that job any more. They put me back to the store, but I told my mom I wanted to get out of it because they hurt my feelings. All I heard was other people told my friends what happened, and they laughed at me and called me a bunch of names, and I didn't care for that so I wanted out of there."

Susan talked about how her family encouraged her, "Mom and dad just said, 'Try, come on you can try. You can do it, try.' and I said 'Okay, I'll try,' and they'd go, 'Good you did it' I felt happy." Her brothers and sister would encourage her also, "They'd go, 'Come on, just try. We wanta see if you can do it.' So I said, 'Okay' and I did it. Like swinging on a rope. Oh, that was the scariest feeling And I went 'plunk'."

Susan described what retarded means, "It just means you're slow.(crying) Well, mom says there's some things she don't know, like she don't know how to play a piano, and there's some things she can't do, so it just means you're slow."

Every time The participant-observer saw Susan, Susan mentioned the two boy friends that she used to have. She sounded sad when she said, "But I wanted to know someone before I got engaged or something. I like to know 'em better than - like Nick, he proposed to me, but his mother don't believe that, so (sigh). I wouldn't want to marry him and then find out he didn't love me. He would have to cope with my being sick a lot. I've been hurt two times. I don't think so. Be happy being single, I think. I don't know. It would be nice, but I know I can't do that."

When Susan was asked what made her feel good, she replied, "All the work...well, all the things I can do, like creweling and candlewicking. Sounds wierd when they call it candlewick - you think you put a candle on there or something."

Describing a happy life, Susan said, "Happiness is being happy. Happiness is being alive - doing things. I would like to fly, but my parents won't let me. I wouldn't fit in my seat. (Susan is very heavy.) I'd like to visit my friend in North Carolina. I would also like to go on a cruise like the Love Boat to Hawaii."

Life History of Bobby (Participant on the Regression Line)

Bobby was the second child in a family with three children. His sister was two years older, and his brother was three years younger. At three weeks old, his mother asked her doctor about Bobby because he had the same perpetual grin that she had observed on retarded children in the hospital where she had worked. The doctor assured her that Bobby was all right. When Bobby was a few months old, he developed a high fever with a rash. The doctors said it might have been meningitis. It left him with partially paralyzed vocal cords.

Bobby's mother worried about him and wished that she had some guidance in knowing when and if to spank him. She wondered how much he understood when she told him not to do something. She had no one to talk to. However, she and her husband agreed that if Bobby were asked to do something, he would be expected to do it, and that he wouldn't be allowed to talk back. Bobby's sister says that her father is a perfectionist, and what he expected of her and her youngest brother, he expected from Bobby, with allowances for his limitations, of course. All the children ate with a fork, including Bobby. When the family went camping, Bobby was expected to roll up his sleeping bag like everyone else. When they got home, his dad would re-roll his sleeping bag so it could be put away.

Bobby's mother also worried about the effect of a handicapped child on her other children. Everyone looked at Bobby because he acted different; he was awkward, and he couldn't talk. His sister says, "He was my brother first and a problem second." Her loyality overcame her embarrassment. She and her other brother would bring friends home and let Bobby join in their games. When they were teenagers, Bobby played baseball with his brother and his friends. When Bobby's brother was sixteen, he stopped taking Bobby to the beach with him because he met girl friends there, but, once in a while, he would say, "Bobby, let's you and I go to the beach by ourselves." Bobby and his brother are still close. They talk on the telephone about once a week. If his folks are out of town, both his sister and his brother call to check on Bobby. Bobby finally told his sister that she didn't have to call; he would be all right.

Other than the worries mentioned, Bobby's mother had little trouble as he was growing up. At first Bobby cried during toilet training, but he had a double hernia and after it was operated on, he was fine. Until he was ten, he wet his bed when he was upset, but his mother understood, for she had had a similar problem as a child.

Bobby's parents always tried to provide the care that he needed within their limited budget. They took him to speech therapy. When they heard about a clinic that treated retarded children with a pill, they investigated it, but their doctor said that the treatment was purely experimental, and they would have to leave him at the clinic. Bobby's parents didn't pursue it.

In order to provide for Bobby's religious training and his socialization, his mother tried to find a church that would accept him. She taught Sunday school as her contribution. When the children began to read, and Bobby couldn't keep up, he wasn't included, so she quit.

When Bobby was almost five, he started school. The other children made fun of him, and he didn't want to go. He cried so much in kindergarten, that the teacher would call upon his older sister to come and make him stop. His sister recalls that she didn't know what to do either. The first grade was no better. Once his teacher slapped him in the face because he wasn't paying attention. Bobby's mother found out about the slap from the parents of the other children, for the children were very upset.

The school system started special classes and decided that Bobby should be placed in one. The principal called Bobby's mother in for a conference. As he told her about the class, he remarked, "Some were given brains, and others weren't." Bobby's mother recalls the incident saying, "I cried all the way home; I was so upset. Ted [her husband] called the doctor, and the doctor called the principal and bawled him out."

Bobby started going to the special class at a school across town. His mother took him and showed him where to get off of the bus. After he had been riding the municipal bus for a week, a taxi showed up in the driveway. The driver explained that, according to the law, the school district had to provide Bobby with transportation. She checked his story, and Bobby rode to school in a taxi. Later, there was a school bus, and Bobby had to ride for hours when he could have been home in fifteen minutes if he took the public bus.

In spite of the long bus ride, Bobby benefited from the special class because he felt more at ease in it, and he had a good teacher. Bobby was shy and wouldn't talk, so his mother and teacher worked together to help him overcome his shyness. His mother wrote down what the family had done on the weekend, and his teacher was able to get Bobby to talk about it in class.

Learning was difficult for Bobby; one day he learned something, and the next day he did not remember it. He was slow to understand. If he was shown how to do something, he understood it, but he could not explain it in words. His parents tried to help, but they didn't know how much he retained. Another problem was the teasing he had to endure. Bobby's mother said, "When he was in elementary school across town, a certain group always made fun of these students in their classes, and that's kind of hard to put up with, but he survived it."

Bobby always liked to work with his hands. His mother said, "He learned that from the time that he was in the playpen, when he got a little hammer for Christmas." His father recalls, "He always wanted to build stuff, so we bought him a little jigsaw, so he could saw a board and made sure that he had a lot of small pieces of boards to saw out and nail. He could use his little jigsaw, saw out boards, make boxes, and things like that. He's still got the jigsaw, but he's mechanically minded, takes care of his bicycle very good, and he has mechanical aptitude. I mean, he knows what wrenches to use and stuff like that." Bobby's mother added, "He loves to paint. He loves to paint those pictures by numbers. He likes to do things with his hands, and he's good at typing certain things. He can copy things on the typewriter."

In junior high school, Bobby took woodshop. His parents were concerned that he might get injured on the big band saw so they made friends with the teacher, and he kept an eye on Bobby for them. Bobby was interested in sports and got good grades in physical education. He didn't seem as smart as the others in the special class and didn't seem to learn as well, but field trips and working with his hands seemed to help him learn. He still can tell you about those types of lessons.

Bobby's parents were not pleased with Bobby's high school training. His mother said, "I felt that Bobby went all through high school carrying great, big, thick books back and forth that he couldn't read one word in, where I felt if he were working with his hands, which he loved to do, and he was good in woodwork, and he was good in lapidary work and things like that in high school, but still they didn't seem to stress any of those things that would have helped him later on that he might have gotten some work, instead of everything out of a book which he couldn't read."

Bobby's father continued, "That was the school's fault. They didn't have any vocational training. It was supposed to be all book-learning, and of course they said that he would never be able to hold a job because he couldn't read. But I said, there're a lot of people who can't read in the United States, and still they have jobs. They have responsible positions, some of them do. They're laborers or they're construction workers, and they know how to do things, and just because they can't read--it's a handicap for them--but still, in their minds, they know what they are doing as far as work is concerned. Therefore, actually, the years that he was in high school were just wasted, because all he did was carry his books and sit in the classes and listen and that was all, and if he'd had woodshop or machine shop, or some other vocational course, he would have been trained for something." However, Bobby did work in the school cafeteria, and now he does have a food services job. One may have helped the other.

Bobby did have a social life in high school. He had a girl friend that he took to the school dances and sports events. Bobby's mother describes one formal dance that Bobby and his girl friend went to. "We tried to make it as though they were like everyone else; you know, bought a nice corsage for her. That was her first one, and that was thrilling, and they enjoyed each other's company. Then, of course, when the dance was over, we picked them up and took them home. I don't think they danced; I think they stood in front of the refreshments table and talked and nibbled. Didn't you, Bobby?" Bobby was listening to the story. "Nope," he replied.

"Whatever happened to his girl friend?" Bobby's mother was asked. She replied that his girl friend became too demanding, and he didn't want to go out with her any more. She said, "Bobby didn't want to go out with her any more, so he didn't. I told him he didn't have to, and so Johnny met her, his friend Johnny, and so Johnny called one night and said,' Can I take Sandra out?' and Bobby said,'Yes, you can have her.'"

Now, most of Bobby's social life is sports oriented. His father explained, "He can read all the baseball scores, the baseball teams, the football teams, but he has problems reading other words, and we tried ways

to teach him how to read, how to sound out the words, but he has his problems with that, but ask him the baseball or football scores for the last year, and he'll tell you. And otherwise, he's very sports-minded, that's his main interest in life."

Bobby's mother agreed, "We started when he was twelve years old. I learned all about baseball so he could learn all about baseball (laughed). The two of us have loved it." Bobby goes to the baseball stadium in the city by bus with his friend, Johnny, and his wife. (Johnny's wife is not Bobby's old girl friend.) Johnny is handicapped also. Even though Bobby gets angry with Johnny when Johnny tries to dominate him, they get together for the baseball games.

Bobby loves all sports and he buys season tickets to the football and basketball games of the university where he works. Once, when he did not get the right amount of basketball tickets, he asked his dad to call and check on them. Bobby does not make those types of calls because of his poor speech. He reminded his dad about making the call about six times on the weekend and, on Monday, when Bobby came home from work, the first thing he said was, "Did you call, Dad?"

Bobby takes the bus chartered by the university to its football games. He likes to take the first one because it serves food and drinks. Bobby said, laughingly, that when the team beat its rival, they served free drinks. He goes to the basketball games with his friend next door who is retired. Bobby's windbreaker sports the university name and colors. Bobby always goes to the carnival held by the university to raise money for a children's camp. This year he was very excited about the carvival, and he went both daytime and evening.

Each weekend, Bobby does the same thing. He gets up early and goes for a bike ride sometimes with his friend next door and sometimes by himself. He rides from fifteen to twenty miles and knows all of the bike paths. He stops to watch a game at the junior college on his way home. He comes home for lunch and rushes out to some other sports event. Each week, he buys a newspaper and the TV Guide so that he will know what sports events are on television. He plans his other recreation around the games he wants to watch on TV. He types out the game schedules. If he is invited to go somewhere, he first checks his schedules, because the game he is attending or watching on TV has first priority.

Only one thing is more important to Bobby than his sports events and that is work. When he had a chance to go to an Olympics basketball game, he turned it down because his boss had gathered the workers together before the Olympics and told them that no one was to ask for time off during the Olympic games. Therefore, Bobby felt it would be wrong to ask for an afternoon off.

Bobby's work history started at a workshop. His mother got him the job because she would not be free to come and go if Bobby did not have a job to go to. The man in charge of the workshop was very patient with Bobby. When Bobby couldn't read 'yellow' and 'green' for color coding wires, he showed Bobby so he could learn. When the workshop didn't have

enough business, they let their workers go, and Bobby had to find another job.

Next, Bobby worked for a department store that was noted for hiring handicapped people. He worked as a custodian for nine years. The clerks relied on him to get things off top shelves and take care of the pet department; it was a good experience. He and the lady that opened the store in the morning had worked out a plan. If she didn't open the door in the morning, it meant that something was wrong and Bobby was to go to a telephone and call the police. He carried the number with him and felt as if others were depending on him. One time he saw someone take some suits from the store. He got his boss, and they stopped the man just as he was putting the suits in his car. Eventually, the store went out of business, and Bobby had to find a different job.

Bobby had a friend who worked in the kitchen at the local university, and when he heard that they needed a diswasher, he brought an application to Bobby. As Bobby's dad tells the story: "We filled out the application, and the university called, and we went over for an interview. Bobby wanted to try out on the job, and so he was to start working and try out on this job because he had never done anything like this in kitchens before."

Bobby's mother continued the story: " The first few days that Bobby went to work on this job as a pot washer, it was all strange to him and he didn't get much help, and it was very difficult. After three days he didn't want to work there any more. He couldn't seem to keep the pots washed fast enough for the different cooks that needed what they needed to cook that minute. He would come, we would pick him up at night, and we knew he had been crying; he was very upset, sick to his stomach, and he couldn't eat his meals when he got home, he was so upset. So after three days we decided that wasn't for Bobby, and I called and told them that Bobby couldn't work there any longer because there was too much pressure on him, and he wasn't getting hardly any coffee breaks, which he doesn't drink coffee, but he wasn't getting any breaks." She said to them, "'I'm going to terminate his job right now. I can't have him treated that way. I don't want him spoiled, but they could be kind to him until he gets the hang of things.' They said he had to work ten days more for any good record, so Bobby said he would."

She told Bobby, "We'll check it off the calendar every day. You've only ten days, and that'll go real fast, and then we'll look for another job. If you work real hard at your job, the best you can, I'll plan a trip to Hawaii."

"I crossed off on the calendar every day that he went to work, and four days later, he came home and said, 'Mom, guess what I did today?' And I said, 'What did you do?' And he said, 'I went in to my boss' office and I told him that I wasn't going to quit and that I was going to work there; I liked it.'"

After about two weeks, Bobby told his dad, "I've got my own way of doing things, dad, and that's the way I'm gonna do them." And he told his boss, "Now, I'm gonna do it this way and it's better for me, and I can get things done and it'll be all cleaned up when I go home from work."

Bobby's dad continued the story, "He got more accustomed to his work; the people he worked with understood his handicap, and they respected Bobby more, and they got to be good friends. The longer he worked, the easier it became. He still works hard, and he's busy all day long, but he is very happy in his job and his benefits, and he gets his basketball and football tickets to go to the games, and he's very happy now. He wouldn't trade his life for any other job."

Bobby's mother said, "He not only washes the pots and pans, but he also cooks probably eight or ten trays of bacon every day and once in a while gets to help peel the vegetables and things for soups, and no matter what they ask him to do, he's right there to help. On his birthday, we went to Hawaii, and Bobby really liked that."

Bobby said, "I didn't want to come back. I wanted to stay over there."

"So every morning when he goes out the door to go to work, he yells,'Aloha,'" his mother concluded.

Bobby has a routine each work day. He leaves his house at 6:45 in the morning, taking a half hour bus ride to the university. He arrives at 7:10, eats breakfast, and begins work at 8:00. If the pot washer doesn't work, Bobby fixes it himself. After ten years working in the kitchen of this restaurant, he feels as if the machine is his. He brings tools from home to fix it. At 1:30, he eats lunch alone and returns to work at 2:00 He leaves work at 4:30 and arrives home at 5:30. When he began the job, he made $3.00 an hour and now he makes $6.25 and gets retirement and health benefits. Bobby is a very responsible worker. At times he leaves for lunch at 1:35 instead of 1:30 but he always returns to work at 2:00.

Bobby not only derives satisfaction from doing a good, conscientious job at work, but also enjoys comraderie with his fellow workers. While he was leaving for his lunch break, a young woman aimed a dolly full of trays at Bobby and pushed it toward him, fast; they both laughed. "She's a student," he explained as he greeted several other student workers and they him. When the workers decide to get a softball game going after work, Bobby is always included. At one of the college basketball games, he trained the binoculars on three of the pretty cheerleaders and explained that they were friends from work.

Just as Bobby likes to have a routine on weekends as well as work-days, so does he also like to be organized in most of the tasks he performs. He doesn't mind the tediousness that is necessary to make his life run smoothly. He has a system of classification in his room; all cassette tapes are in one place and all sports mementos in another. He uses dimes for his bus fare in conjunction with his handicapped bus pass, and he will tell his father, "I've got to have more dimes; now, when you go to the bank, bring me some more dimes." Since his dad is retired, Bobby relies on him to fix his bicycle. Bobby got a new tube to fix his tire and he kept asking, "Dad, did you fix my tire?" Bobby was worried about not having his bicycle for his Saturday ride. Bobby has a book in which he keeps track of expenses. He'll take out the book and say, "Look what I

paid for haircuts in 1960." He keeps track of every paycheck he has gotten since he began working. Once he started to write down all of the multiplication tables through the twelves; his father accidentally threw his papers away, and Bobby just started writing them down all over again. Even Bobby's meals are scheduled, but as his sister claims, by some inner clock. He can tell time by his hunger pangs. Besides his regular meals, he likes to have his milk and a sandwich at about eight or nine at night. When there is only a half gallon of milk in the refrigerator, he'll say, "Dad, we're gonna have to have milk."

Bobby has favorite television programs that he watches. He watches mostly public television, and he learns how to do things when they are demonstrated. For example, he watches a program about repairing and building houses; then he will tell his dad, "Dad, you should do it this way; this is the way the man does on the television." He also loves to listen to all types of music. He tapes what he likes and keeps his extensive collection classified in his room.

When Bobby was in school two projects captured his imagination and he has made them into hobbies. Once his class went to the airport, and they were able to go through an airplane. Now he listens to the airport control tower on his short wave radio at home, and he likes to take the bus to the airport and watch the planes land.

The other project was studying about Indians; the class went to the Indian museum, and they drew pictures of Indians and Indian atifacts. Bobby calls Indians his brothers, and the family, including his sister and her husband, camp on the Shumash Indian Reservation. The Indians come into the campground and have coffee with them.

Since Bobby's vocal chords were partially paralyzed when he was an infant, he avoids talking to most people. If his parents are around, and Bobby wants to tell a story, he relies on them to tell the bulk of it. He often gets impatient with their inaccuracies, corrects the details, and finishes the story himself. He is not reluctant to talk to his family and friends.

When Bobby talks about himself, he tells three incidents that he remembers vividly. The first is one in which he was hurt. He was riding his bicycle with the man next door, when Bobby went flying over the handle bars and his seventy-one-year-old companion landed on top of him. The only thing broken was the bicycle, but Bobby remembers the trauma and the broken bicycle.

In the other two incidents, Bobby is the hero. Once a woman got out of her car leaving the motor running. The car started moving, and Bobby quickly turned off the ignition. He came home so excited that it took his mother a long time to find out what happened. The final incident occurred when Bobby was in junior high school, almost thirty years ago, but he remembers it well. Some policemen had put two boys in their car and then ran after a third. The two in the car started to run away. The policemen shouted to Bobby to stop them, and he and his friend did. He beams while his mother tells these stories at his prompting.

Not only can Bobby act quickly in some instances, but he has also developed problem solving skills to help himself get around his inability to read. For example, his mother bought him a paint by numbers set. Since he couldn't read the names of the colors very well, he cut out the numbers and pasted them on the paint containers so he only had to match numbers. He has learned to survive without reading and he has no motivation to read, now, except for things related to sports.

When Bobby's sister describes him, she thinks of his child-like qualities. She says that he puts his shoes on the right feet now, but sometimes he doesn't put his pants on straight, and he forgets to comb his hair. He loves the excitement and joy of holidays. One Easter, she saw a big bunny and impulsively bought it for Bobby, even though he was a grown man. He loved it and put it in a place of honor in his room. He takes great pride in earning his own money and delights in giving money to each member of the family at Christmas.

His parents see him in a different light from his sister. His father says, "He gets up by himself in the morning, very quiet, gets his breakfast and goes out the door, and he's very punctual, comes home at the same time every night, and he's never late. If he's going to the store, if him and his brother were going to the store to buy some candy or something, it had to be done just right, just at the same time; he couldn't wait a couple of hours to go, it had to be done right then and there, and so he's been very punctual. He's self-reliant and gets along just fine on transportation and busses and does all right." His dad is also proud of the way Bobby does his job. He says, "He's good; they treat him nice, they pay him a good wage, and they respect Bobby, and they like Bobby. I talked to the boss the other day and I asked how Bobby was doing, and he says, 'Just fantastic. Don't know what we'd do without him.' He's conscientious about his work and I'm sure he does the best he can. As long as he's happy in his job, that's the most important thing. There aren't many people that are happy in their jobs. I hope he can stay there until it's time to retire."

Bobby's mother adds, "They're forever giving him raises," and his dad echoes, "We're so surprised, he gets merit raises plus when the faculty gets their raises, he gets a raise too. He makes more money than me when I retire. Of course it's all put away for him; all his money's invested so that when he retires he will have no worries. I mean, he'll be no burden to anybody. He's doing all right and of course he has no expenses. Like he doesn't have a girlfriend or he doesn't have a car or he doesn't drink, and he doesn't run to movies or spend money foolishly, he doesn't gamble or anything like that, so actually the money is just put away for him. When he gets ready to retire or if he gets sick or something, he has money that people can use to take care of him. Set up so that he'll never go without. He will not be a burden to the state or the city or anybody. He will be independent; he'll have money to pay for his rooms and his board and his food, and his clothes, so in that way we want him to be independent. Of course, his brother and sister will see that he's taken care of, but it won't cost them anything. Bobby will have his own money to do it with."

Bobby is very attached to his parents, especially his mother. He panics in any emergency concerning their health. His parents appreciate

his concern for them and his love, and in return, they take care of him without resentment. They have found a way to keep their lives on an even keel. Bobby's mother worries about him when he is out at night at a sports event, coming home on the bus, but she endures it. Bobby's parents give him freedom within certain boundaries and all runs smoothly.

To people, other than his family, Bobby appears to be a tall, nice looking man, and does not give the impression of being retarded. He aparently has a speech problem, but otherwise he shows the world a man with a pleasing personality, a good sense of humor, and a good social sense. He projects a strength and a sense that he knows what he is doing.

Bobby Talks About Himself

The most Bobby says at one time is just a sentence. Because of his speech problem, he lets his parents talk for him most of the time. He will mention a topic and say, "Tell them about..." The following is an interview at Bobby's work when his parents weren't there. The interviewer will be denoted by an "I" and Bobby by a "B."

I: What do you do on your job?
B: I do baking, and I help the cooks sometimes, and I do a lot of other stuff.
I: Wash a lot of pots and pans?
B: Right, wash a lot of pots and pans. Get tired, too, sometimes.
I: It looks like you're moving pretty fast.
B: I have to move fast.
I: There's always lots to do , huh?
B: Yeah.
I: How did you get this job?
B: A friend of mine got it for me.
I: When was that?
B: It was in 1975, I got it.
I: You've been here since?
B: Yup, This coming Christmas, I'll be going on my tenth year.
I: How do you like it?
B: I like it good.
I: Did you have other jobs?
B: Yeah, I was working at a workshop.
I: At a workshop?
B: Yeah, it was for handicapped people, and I was working at Grants department store for nine years.
I: And how does this job compare to those?
B: I like it.
I: You like it better?
B: Yep
I: What do you do when your not working?
B: Off work, I go for a bike ride and watch TV.
I: Is that the machine that you fix when it breaks down?
B: Yes
I: How do you do that?
B: With a pair of pliers, screwdrivers.
I: How did you figure out how to fix it?

B: Nobody taught me; I just learned my self.
I: Where do you get the tools?
B: I've got tools; I've got my own tools; I buy them.
I: What about sports? You're into sports aren't you?
B: Yup, I go to my high school, (he names a university) games.
I: What's your favorite team?
B: Raiders.
I: What would you say are the most important things in your life?
B: Uhhh, I don't know.
I: What do you like to do, what do you get the most enjoyment out of?
B: Working.
I: Working?
B: Yup
I: Do you like being here as much as you do when you go home?
B: I like to be here and at home.
I: How does it make you feel to have a job?
B: Good!
I: What will you do when you leave today?
B: I'm going to go to my locker, locker room, get dressed, and go home.
I: And then what?
B: I will eat dinner, look at TV, and go to bed. Get up at five o'clock in the morning.
I: Five o'clock, huh?
B: Yup, five days a week.
I: Are most of the people who work here students?
B: Oh no, uh yeah. We got some employees work here permanent, and students come and go.
I: I guess they're glad to have you not come and go.
B: Right (laughs). Ohhh, I'm tired.
(Other employees leaving and saying goodbye to Bobby.)

Life History of Lori (Participant on the Regression Line)

Lori was the most beautiful of four children born to a successful, white collar worker and his Dutch wife. They had a boy three years older than Lori, another boy six years younger than Lori, and a girl eleven years younger than Lori.

When Lori was two and a half years old, she had measles encephalitis. Lori's mother blamed their family doctor for not giving Lori gamma globulin when her brother came down with measles. She also blamed her husband for being too cheap to have a good pediatrician for the children. Lori's parents desperately sought help for her when she went into convulsions. They were turned away from the local hospital because the staff feared that she had polio. Lori was finally admitted to a university medical center far from her home. Lori had stopped breathing when they rushed her into the emergency room. She stopped breathing a second time, and the doctor didn't know how much she would improve. Lori had damage to "the back of her brain". Her mother said, "She was such a pretty little girl, I hoped she would improve."

Lori's progress was slow; she had seizures, and she had trouble getting along with other children. The doctor warned that Lori might have temper tantrums because of the brain damage. Lori was tested by a psychiatrist, and he said that she would do all right, but that she couldn't be forced.

Lori had had temper tantrums before she had measles encephalitis. When she banged her head on the living room rug, her mother would put her on the kitchen floor so her head banging would hurt, and she would stop banging her head. Now Lori was even more difficult to discipline because her mother didn't know how much she understood or what she was able to do.

Lori's mother recalls the difficulties she had with Lori and her temper. "Lori could never have a companion. She didn't grow up with someone her own age that she could play with. She didn't seem to be able to get along with other children at all. Either the mothers would get upset with her or the child would get upset, and when Lori got mad, the first thing she would do is hit. It made it rough to try to have friendly neighbors when they didn't exactly like Lori. Lori was hard to sharing things, and if the little girl next door would take her doll, she would get angry, and I believe there was one time that she took the little girl's doll or she took Lori's doll, and Lori got upset and hit the little girl, and the mother said, 'Keep your idiot, fat child or handicapped child out of my yard' and so we had to keep her away from other people's children. She couldn't even play well with her own cousins because they couldn't relate to Lori because you couldn't really talk to her when she was little. It was just simple, simple language that she could understand and relate to. And I think Lori's still the same way even though she reads a lot."

The family moved frequently as Lori's father was transferred from one branch of his office to another. Lori went to several different elementary schools before the family finally settled in a small community. When it was time for Lori to start school, her mother didn't think Lori was ready,

but, her mother reasoned, Lori would be around other children so she enrolled Lori in kindergarten. Lori's mother helped her, but, remembering the admonitions of the psychiatrist, she didn't push her. Lori's mother felt that love and kindness would help Lori progress more than pushing her. Lori repeated kindergarten.

Lori was in the fifth grade when her family finally stopped moving. Her fifth grade teacher believed in pushing the children, and Lori reacted by having more seizures. The other children picked on Lori, called her names, and lifted up her skirts and embarrassed her. Her mother took her to the Child Guidance Clinic at a local university for evaluation and help. The school district placed Lori in the special training class. Her mother said, "I was so happy about it because I didn't know they had classes like that. Lori had a good teacher. She really loved those children. She treated them like they belonged." Lori's mother was not given the test results, and the people at the Child Guidance Clinic did not answer her questions. They used medical terms she did not understand.

Lori's memories of the special class and later a special school focused on her relationships with the other children. The children in the regular classes teased her and called her "cootie bug" because she was fat and didn't keep herself clean. Her mother remembers that she would tell Lori to clean up but Lori refused. Lori recalls that she didn't have friends in school because she would hit other children for no reason. One father in the neighborhood brought charges against Lori for hitting his daughter.

Perhaps part of Lori's problems stemmed from the conflict in her home. Lori recalls, "My dad always babied me. If mom were punishing me when I was little, I would run to dad and sit by his knee, and he would not back my mom up. I was spoiled by my father. When I was ten, I would try to eat as much as he and would get sick sometimes. When it was time to go to bed, I would sit by my father's knee and say, 'Please may I stay up?' and he would say , 'Yes.' My mom would say, 'No, she must go to bed,' and sometimes my father would hit my mother. I would have a seizure if I got upset about dad hitting mom." Lori's dad would watch movies on TV all day Saturday and Sunday. He would get angry when the kids were noisy and he wanted to watch TV. Lori said, "Dad would use an army belt on us, and we would bleed, and mom would have to take us to the doctor."

Lori gets along better now with her brothers and sister but said she wasn't nice to them when she was little. "When I was young, I was on a lower level than my younger brother and we would fight. I would tell my father that my older brother did something to me, and my father would hit him. You see how awful I was? My brother would tell mom, and she would spank me and tell me to stay in my room. I needed that because my father spoiled me. When I'd get mad at mom, I would go break something that belonged to my brother. Mom says I got most of the attention when I was little. I feel bad about that now, but my younger brother tells me to forget about that. That happened when we were kids. He says that when he gets married, I could live with him. I wanted to live with my older brother and sister-in-law, but my mother said she wouldn't let me ruin their lives."

Lori's mother worked, and Lori had a baby-sitter. Once, when Lori was eleven, the baby-sitter went to the store, and the man next door came over. He was drunk and tried to kiss Lori's genitals. Yet when Lori's mother was interviewed in 1959 and Lori was thirteen, and she was asked if she worried about Lori's sexualtiy, she replied that Lori had never asked about sex. Lori's mother continued saying that she had asked a doctor about telling Lori the facts of life, and he had said not to tell her about sex until she asked. Her mother said, "I tell her what ladies don't do--to keep her legs down and she doesn't understand. She looks older. I'll worry more when she's fifteen." Yet, when both Lori and her mother tell about Lori's being molested, they both say that she was eleven years old at the time it occurred.

When Lori reached high school, she was having seizures so frequently that she was sent to a special high school for handicapped children. He mother recalls, "I think, when she was in high school, even, I had to go to school, and she would be in a comma for three hours." Before she moved to the special school, Lori tells of an incident in which one of her teachers gave her a grade of B that she did not deserve. The other students were angry when they saw her report card, and one hit her in the face. She went to the principal and told him about the teacher's giving her an inflated grade. The teacher changed the grade to a D. Lori said that she would rather get a poor grade than be hit in the face.

Lori was not popular at the special school either. She would be thinking about something, and then just go over and hit another student for no reason. One girl that Lori had hit was scared of Lori until their last year in school. The administrator asked Lori if she could help buy the girl a dress for some school occasion, because the girl couldn't afford one. Lori said yes, but at first, the girl didn't want to take it. Lori, the girl, and the administrator talked it over, and the girl accepted it. Lori felt better. When lori grew older, she just stopped hitting others. Lori did have some positive school experiences at the handicapped school. She said, "I learned more because the classes were geared to your pace of learning. I didn't feel so stupid when I understood. I liked a knitting class that a lady in the office had because after the lady showed me how to cast on, I could show the others. I bought a book on knitting and worked on it by myself too." When it was nearing graduation time, Lori was warned that she could not graduate unless she passed a certain course. With the help of a student tutor, she studied hard and did graduate from high school.

When Lori was a teenager, her parents were divorced and she lived with her dad and stepmother for a few years. Speaking of those years, Lori says, "When I lived with my dad, my mom would tell him to treat me more like an adult, but when I lived with my mom, she treated me like dad did--more like a child. My stepmom helped me a lot with that; I told her that I wanted to think for myself, and she influenced my dad. I have a hard time with my mom, the way she talks to me, like I can't do anything."

Lori received training in a workshop while she was in school and for a year afterward. She tells about her experience there, "I was always good at assembly type work. Through school, through a class for training, I

worked in a workshop for a whole year, from September through June of the following year, and I liked working there. Except when I went back when I got out of school, I had too much money, I mean, I made too much money to do the slow work because I was too fast for that, so they put me on soldering, but I didn't go for that much. When you take the thing and pick the stuff off the wires, I do too much, in other words, or when I was soldering the solder wouldn't melt in a nice way. I always did it in an awful way; I never was correct, so I just gave up on it. Then I just quit going." During another interview, Lori said that the person in charge was not patient with her and hurt her feelings and so she quit.

After graduating from high school, Lori returned to live with her mother and stepfather. Lori remembers asking her mother about sex, but her mother was too embarrassed to talk about "that part of life." Lori asked her stepfather about it, and, she says that he brought home pornographic movies and raped her. Lori remembers running out of the house and crying. Her mother maintains that Lori has confused her step-father with another man, that her step-father did not have intercourse with Lori, although Lori wore seductive lounging pajamas around her stepfather. Lori's mother also accuses Lori of having incestuous feelings toward Lori's real father.

Lori's mother tells the story this way, "After Lori had sex with her boyfriend, she kept telling my husband,'I need sex.' And I kept telling her, 'For five years, when your dad was gone, I never had sex, and you don't need sex. It's all in the mind.' I says, 'You can live with it; you can live without it. But when it's not there, you don't have to have it.' And she felt that she had to. And now, of course, I think she's totally against it. She has a fear of men, boys; she won't kiss her brothers, she only shakes hands with them. I really feel that Lori is still quite a bit like her father. I can't say that he's oversexed, but he was more oversexual than I was. I'm more the affectionate puppy type, like my husband is now. Like a big puppy. And I'm that way, not demanding of sex, and I think Lori thinks that she is because it's supposed to be natural."

Lori was going to a therapy group for women who had been victims of incest. She was able to talk about her feelings of anger, guilt, and betrayal. The leader of the group says that the details that Lori remembers about her stepfather's raping her could not have been just imagined.

Lori says she was sexually abused by her step-grandfather, a boyfriend, as well as a man whom her mother encouraged her to date. Lori met this man at a race track. Lori and he had been laughing and talking, and he had asked Lori for her phone number, but she had refused to give it to him. When Lori and her mother got home from the races, her mother told her about the date she had arranged for Lori and the man. When Lori said she didn't want to go, her mother assured her that it would be all right. On their date, he forced Lori to perform oral sex and raped her.

In a work training program, Lori finally met a man whom she wanted to date. Lori's mother says that he took money from her and took advantage of her sexually.

Because of the traumatic sexual experiences that Lori has had, she experiences deep depressions. She says, "I was raped three times, and when I get depressed, I think I want sex, and I feel I'm a dirty person. I have to learn that I'm not a dirty person because of the experiences that I've had." Lori has been in and out of mental hospitals during her adult years. When she begins to think of herself as a dirty person, she injures herself. She has attempted suicide three times. Once she ignited lighter fluid that she had poured all over herself. She had to have skin grafts for the burns. Lori cannot see herself getting married or having children. When a man is friendly toward her, she gets very frightened.

Lori has had different living arrangements since leaving her mother's home. She lived in board and care homes. While living in one board and care home she had two positive experiences. She made friends with a man in his sixties or seventies. When his sister had to go somewhere, Lori would stay with him. Lori says that she made sure that he didn't drink while his sister was away. He and his sister have moved to the Midwest, but Lori stays in contact with them. When Lori is feeling low, she calls him, and he pays for the call. He and his sister wrote Lori recently telling her how proud they were of the success that she was having in a work program.

At this time, also, Lori enrolled in a reading class in a junior college near the group home. Lori earned a B+ in the class and was thrilled; she had never earned such a good grade. Her mother had told Lori not to expect to go to college, and she was happy to prove her mother wrong.

For a while, Lori was living with her grandmother, but that was not working well. Then Lori's mother learned about a program in which a handicapped person could live with a senior citizen and they would help each other. It is called a "companion program," and is run by a local hospital. Lori enrolled in it, was trained, and then placed with a senior citizen. She was required to attend weekly meetings to help solve any problems that arose on the job. The senior whom she lived with provided a home for Lori in return for twenty hours of work per week. Lori received a Social Security check that she had to budget to pay for her food, telephone, clothes, and other expenses. At first she depended on a lady at the bank to help straighten things out when she was overdrawn, but she has since learned to reconcile her own checkbook with her statement and even to subtract the service charge.

When Lori first started working for her senior, she was on a lot of medication: Dilantin and Phenobarbital for her seizures, and an antipsychotic, Chlorpromozine, for her mental problems. Her senior complained that she would almost fall asleep with her head in her plate. Lori's counselors from the companion program and from the regional center sent her to a nearby university for individual and group therapy. There she began going to a different neurologist who reduced her medication. She became more alert and was a better worker.

The senior citizen for whom Lori worked was a very particular housekeeper and was not satisfied with Lori's work. At first, Lori resented her senior's criticism. However, the senior's daughter is a

social worker, and she helped her mother understand Lori and helped Lori cope with her mother. Now, Lori is a very particular housekeeper and is very proud of how well she has learned to cook and keep house.

Because of Lori's poor memory, she had to figure out strategies to remember appointments and what she needed to do around the house. She kept a date book and included her work schedule in it. Monday, she cleaned the dining room and kitchen. Tuesday, she cleaned her own bedroom and the den, and on Wednesday she cleaned her companion's room. She wrote down the things that she did every other week such as vacuuming the couch and drapes. This strategy suggests a certain inflexibility, but Lori is more comfortable with routinization. For example, she likes to go to the same restaurants; she has worked in the same math book for years because she starts over each time she takes a break from it and returns to work in it again; she took the same math course over in junior college because she wanted to finish the book even though there were sections her teacher skipped because of their lack of relevance; when she types, she throws the page away and starts over if she makes a mistake.

Lori also has a language disability; she has difficulties understanding others and expressing herself. This disability contributes to her difficulty in getting along with others, which poses a conflict for her because she derives her greatest satisfaction from helping others. She says about working in the companion program, "I'm so proud of myself having this job, because at the end of group therapy, I said I was going to do this kind of work--helping people--and I'm doing it. The people in the group didn't think I could, so I've written to them to let them know." The biggest problem she had with that job was getting along with the lady whom she took care of and the lady's friend who visited every night. Lori said of the woman that she took care of, "She tells me stories like my mother, and I don't like it. She'll say that I said or did something that I didn't. I have learned in group therapy just to let it go, not try to get the last word. Part of the problem is that I can't follow their conversations. There are words that I don't understand and I get lost and bored. They ask me why I'm so quiet, and I get tense and my shoulders hurt."

On the other hand, sometimes Lori understood too well what her companion and her friend were saying. Because of Lori's disability, her companion's friend was sometimes insulting and whispered about Lori. Lori would become furious and destructive. Once she broke a stuffed bird that her senior prized, and once she scratched herself the length of her thigh.

When Lori became very depressed or upset, she would seek help from everyone she knew. She called this "talking out" her problems. She would call the "hot line," her friend in the Midwest, a nurse from one of the hospitals she had been in, an aunt, and the participant-observer from this research project. The problem with this strategy was that she asked for and got so many differing pieces of advice that she got confused. Her therapist urged Lori to contact only her therapist when she had a crisis.

While Lori was working in the companion program, she began going to a local junior college that had a program for students with learning disabilites. She took reading and basic math and enjoyed school very much.

Lori met a man in her class at school, and they were becoming friends when she became frightened by his actions. He tickled her and this made her nervous. One day when he had said that he would be at home, he took her picture at the college. Lori was with a girl friend and the girlfriend waved at him as if she expected him to be there. When Lori told her companion and her companion's friend about the incident, they suggested that the man and girlfriend might be trying to blackmail Lori. Lori became more frightened.

On reduced medication, Lori seemed to become more paranoid. Two more incidents and her companion's becoming more demanding of her time brought Lori almost to the breaking point. Both incidents had to do with Lori's past sexual traumas. The man across the street and a friend became drunk and were on the sidewalk where Lori and her companion were walking. Lori panicked, left her companion, and ran to the couple next door for help. Lori tried to shake her growing fear by reading a self-help book that frightened her even more. Next, Lori smiled at a man with whom she was riding in an elevator, and he remarked that she had better be careful or she might get raped. Lori became so frightened that she couldn't take her companion on the bus to her doctor's appointments.

In addition, her companion was not feeling well and she expected Lori to be with her twenty-four hours a day, seven days a week. The counselor in the companion program got another girl to relieve Lori when Lori went to school, but her companion was not satisfied with the new girl's work and had Lori scrubbing the floors when she got home from school. Lori had been working with her companion for two years without a vacation. Everything seemed too much for Lori, and she asked the psychiatrist at the univerisity medical center, where she received her therapy and medication, to put her in the hospital. The therapist, the neurologist, and the psychiatrist all gave Lori support so that she could stay out of the hospital, and it seemed as if they were succeeding, when Lori asked her regional center counselor to arrange a vacation for her. Against the advice of Lori's therapist, the counselor arranged for Lori to go to a group home that housed very low functioning clients. The people in charge administered Lori's medication just as prescribed on the bottles, even though her doctor gave them other instructions. Lori says that the female cook put her hand up Lori's dress, saying that she thought Lori would like it. Lori scratched her own face and arms, and the people in charge of the group home were so alarmed that they had her sent to the hospital. Lori couldn't go to the university medical center because it would not accept Medi-Cal. While she was in the hospital, the regional center decided that Lori's problems were emotional, not developmental, and cut off her support. When her Medi-Cal ran out, the hospital had to release her. Lori called everyone she knew, looking for a place to stay, since the reduced SSI that she received from working in the companion program was not enough to pay for living in a group home. Lori could find no one to take her in temporarily. Her father agreed to pay the difference in costs, and she was released to a group home. Her neurologist at the university medical center wrote a letter to the regional center outlining her disabilities, and the regional center reinstated her. In the meantime, Lori remembered an independent living program that a friend of hers was in, and Lori's mother took her to look at it. She has asked her regional center counselor to help her get into the program. She has

contacted the junior college she attended before and will return to classes when she is placed in the independent living program.

Lori still sees her companion and her companion's friend when her father takes them to lunch. She has gone to stay with her companion's friend a couple of times. They seem to get along much better as friends than when Lori was an employee. Her companion is selling her house and has gone to live in a retirement home near her daughter.

The last major issue in Lori's life is her relationship with her mother. Lori loves her mother and misses her when she doesn't see her, but Lori was afraid to be with her mother because she tells Lori that she is handicapped and that there are things she can't do.

Lori's mother describes her dilemma, "I think that's been the hardest thing, to have Lori accept the fact that she does have a handicap or, would you say, a disability. She wanted to say there's nothing wrong with me, and then when I'd try to explain if there was nothing wrong with you, then you wouldn't keeping going into the hospital when you get upset. And other people don't realize you may not have a mental disorder, it's physical, because your brain was damaged when you were a baby from measles encephalitis, so it's something you have to grow with and understand. And it's hard for her, she wants to be treated as a normal adult just like her other brothers and sisters, and it's very hard. I think to this day, she talked to me once about six month ago on the phone, when she had talked to her therapist, and she said she wanted to talk to me. I says, 'Lori, I don't want to talk to these people because you keep telling them that I'm the one that's crazy and I'm the one that needs psychiatric care and that's not fair. You say that about your brothers and sisters. If it were so, they'd be having the treatment.' And I don't think she needs a psychiatrist as much as she needs a neurologist to control her seizures. In fact, that's what a neurologist told me years and years ago."

At the therapy session that Lori's mother refers to, Lori's therapist says that she could hear Lori's mother yelling over the phone at her calling her stupid. Lori wrote a letter to her mother describing how she felt. Lori wrote: "I wish you wouldn't look at me being sick. This is what has confused me most of my life. Like when you call me stupid. Yet I know deep inside my heart and me that I am not sick or stupid. I want you to please tell me I have progressed; it makes me think of myself more and makes me proud of myself more too. If I hear this more, I will think this way more too and progress much more too."

When Lori's mother received this letter, she made an effort to compliment Lori. She did not always succeed. Lori told her therapist in one of their sessions, "She [her mother] called me Sunday and that was the first time, when I sent her the Easter lilies. She didn't even say thank you, and I think my stepfather was the one that had to say thank you, because I had to keep repeating to her, 'Mom, how did you like the Easter lilies?' And I almost was crying, tears was coming down until finally, she said thank you for them."

The letter and the therapy session were before Lori went into the hospital the last time. Lately, Lori's mother has taken her on several weekends and they seem to be getting along very well. Lori has even stayed overnight at her mother's house with her step-father there, too. Lori's dad is still helping her financially and takes her to lunch once a month. He took Lori and her companion out to lunch on Lori's birthday.

There can be no concluding paragraph for Lori's life history because her life changes so much that any generalization is always out of date.

Lori Talks About Herself

During this research project, there were two phases to Lori's life: when she was working in the companion program, and after hospitalization. The same themes were in her conversations during both phases--her relationship with her mother, her feelings about herself, her relationship with men, her work, her school--and running through all of these themes was the impression that she never had an idea of her own, only ideas that others had given her.

The following section will be in two parts: First a therapy session that Lori allowed to be videotaped, and second, conversation also recorded on videotape after she was released from the hospital. Lori was so used to being videotaped that both sessions were very natural.

Before Lori's words are presented, her therapist tells the difficulty that many deveopmentally disabled people have, which Lori has to the extreme. She says, "A lot of the people come to us without any real knowledge of what exactly is wrong with them and what it means. They only have what they've heard themselves called by other people. They don't really have a good sense of their power, like, for instance, the physically disabled have or the blind have. It's always somebody else who's advocated for them, so they don't have a good sense of their own abilities to advocate for themselves in spite of their disability, so they have to deny their disability because they don't see that they can do things in spite of it."

In the following therapy session "T" will stand for therapist and "L" will stand for Lori.

L: I called my regional center counselor, and he told me that I'd have to leave the companion program in about a year, and that worried me a little.
T: Why?
L: It scared me kinda. He wanted me to go on a regular job, and I don't feel that I should go on a regular job until I take the nurse's aide class and get a better education.
T: Whose choice is it?
L: Well the companion program counselor told me it's up to me. Thank God of that. She wants me to get out more, that's what it is too. That's the main reason why she wants me to go to the independent living program. Anyway, when my companion says things that's against me, I just let it go in one ear off the other. The same way with

mom, now.
T: You've been talking to mom?
L: Yup, she called me Sunday and we talked an hour for the first time. Enjoyed it too.
T: But the letter you wrote got upset with her a little.
L: I think explaining everything to her, she understood it more. She knows why I'm staying away, but when she told me I'm doing better, or something, I forgot what she said, but I didn't think that she really meant it the first time when she said it. What I meant is just instead of telling me that I'm stupid, even though I was going to college, to tell me the other way because I'd rather hear it the other way cause if I hear better things about me I think better about myself. Where, the other way, if she calls me stupid, like I used to feel. Like the psychiatrist told me before, I'm smarter than I thought I was, and I'm beginning to see it now.
T: So when she called you stupid, then you felt like you were?
L: At the moment, cause I take things seriously, but later I was able to laugh it off. It's just like that time Grandma, when I wrote in the letter how she told me I was sick, yet when I got to the car with my brother I laughed it off, because I know I'm not sick any more, by the way you've helped me when you explained to me that time, it's always put in my head. And that's what your words explained to me, even though doctors have been telling me that, the words you used explained to me much better.
T: What's been put in your head?
L: Like how dad and mom and the family tell me I'm sick always. Just because I had the measle encephalitis.
T: So you're not going to be sick for the rest of your life?
L: No, I'm not sick any more, no matter what they say. They can look at me as sick, but I don't see myself sick any more.
T: How do you see yourself now?
L: More grown up and more mature in a lot of ways.
T: What about when somebody says," What disabilities do you have because you had the measles encephalitis, because you were sick?"
L: Well, slower at learning, but I'm doing good in the English class and in the reading class; everything's good in my math class too.
T: Why do you think you can learn all this stuff now and you couldn't in high school?
L: I was slower and I couldn't, now I have more of the capability of wanting to learn, too, because I took it, when I was younger, from what mom and dad told me, I was stupid always, so and when kids called me stupid even, I took it that way.
T: So you stopped trying?
L: Uh-huh, so I stopped trying and would give up, and now, more, like I don't give up much. I try again.
T: Do you think being off the medicine has helped?
L: Yes, that's a lot to do with it, too. That's what my uncle has told me. He thinks it's being off a lot of that medicine I was taking, cause I'm only taking five different pills a day now. Just my seizure medication, where before I was taking seizure medication, something to help /me do my thinking, and I think much better without it.
T: It was just putting you to sleep.
L: And that's another way I'm proud of myself, because I'm taking less

medicine too. I'm accomplishing so much more than I ever have in my whole life this past year.

T: Do you think you could have done it sooner, if people had been more helpful?

L: I think so, if they would have treated me more adult and more grown-up. Like mom always told me, you can't go to college, and it was my psychiatrist, he told me to go to college, and I told him I couldn't do it, but he told me, he kept talking it in to me til I went, and I took basic reading skills and got a B+. I never got a B through grammar school, through high school.

T: How about the people in class, how are they now?

L: Everything's going ok-k-kay now. Last week I still was a little scared of Ted, but today when he came up to me I wasn't scared.

T: Why were you so scared last week that he'd do something else?

L: Well it took me time to get over it, the fear. He hasn't touched me since that time because I asked Judy if she'd explain to him and she did. Where like last week he asked, would, I'll call you, and that kind of scared me a little and well I told my companion that if he calls, just tell him I'm not home.

T: Well, that was an awful big step for you from being so scared of men that you couldn't even pass by them on the street to trusting him. But you can be his friend and it's okay. Maybe you'll get back to the point where he can call again and you won't be afraid.

L: I think my companion scared me more. I think that's what it is.

T: I think you're right.

The following are excepts from a conversation after Lori left the psychiatric hospital.

Talking about the companion program she said, "I'm really glad I got through the training of the companion program, cause it helped me understand an awful lot about myself, that I was better off than I thought I was. It taught me to grow up and stand on my two feet a little better. In other words, I'm learning that I can't run to everybody for an answer. I have to make up my own mind and have my own answers. I like to read my Bible every day, because I believe in prayer is the answer. You pray to God for things to get better for you, and if you pray to God, He gradually helps you and answers your prayers. But if it doesn't come right away, just keep praying and praying until it comes, and then thank God when something comes. Like how I want to get more independent and love and respect my mother, it finally came through and I finally did it."

Lori talks about how she spends her time in the board and care home. "Search books, look up the words and then you try to find them. It's really relaxing for me I do this to pass the time, to keep myself occupied, or else I work on puzzles, different things like that in the Dell crossword puzzle book, and I got a Dell crossword dictionary."

Lori tells about what she hopes for her future: "I hope some day that I'll get back to the companion program and back to college again. I love going to college. It relaxes me and helps me an awful lot, helps me learn. I understand what I'm reading, but since I stopped going there, it kind of slowed me down and I got mixed up and when I'm reading sometimes now. I

never could believe it that I got a B+ once before in college and never got a B+ in grammar school through high school."

Lori was asked how long she thought it would be before she went back. She answered, "Probably a year. Dad wants me to stay out at least a year longer to make sure I'm better before I go back. And the social worker told me a couple of months ago that, I think, I'd better stay out a year to make sure I'm better."

Life History of Rod (Participant With a Master's Degree)

Rod was born two months prematurely. It was a breech birth and the doctors used forceps. He developed slowly, walking at fifteen months and talking at three years. When he began talking he had an articulation problem.

When Rod was a year old, his mother had another boy and when Rod was five, she had a baby girl. There were no other children in the neighborhood, and the older neighbors objected to the children's playing outside. Rod remembers, "I remember having fun in the alley, mud, and the garbage. There were mostly older people in the neighboprhood. One lady would come out and say, 'Go back into the house,' and my mother would come out and have a verbal fight with her."

"Most of my memories were good; there were some violent ones. I became a good listener. I could sit up all night and listen to my father. My brother had a much worse time. My mother had married my father and they didn't get along so she left. She didn't like living at home any better, so she came back to my father and immediately got pregnant, and I was born. My reason for being was to keep the family together--the glue. My brother would hold his breath, and my father would beat him. If I embarrassed him in public, oh, the beating I would get. I would watch my brother and sister and see how they got in trouble and avoid doing that. Eventually, I learned how to do things and not get caught. My brother had dyslexia badly. I probably had it a little; my sister had it too. My father would say how much brighter I was than my brother. I was, but there was no need to say it."

"I remember playing in the backyard with my brother. My mother's family lived near us and we would visit them every week. This reinforced home as the only reality. Our town was rural then; trees, big backyards, a quiet, sleepy town. My father was a postman. He'd get up at 5 a.m., and I remember getting up and getting in bed with them."

"I remember dreams and bits of conversation, but perhaps the most important memory was standing by my bedroom window. I would wake up before anyone else, and I would hear the morning doves singing. I was five or six, and the thought came to my mind, 'Is the sound I hear the same as what other people hear? Does my brother or mother hear the same type of sound, or when I look at the color yellow, do they see the same thing I do? I know I have something behind my eyes doing all of this. Does the person that I talk to have that too, or is it a robot or something I've created?' I'm not sure that this made me aloof or shy, but home was my reality: my mother, myself, the furniture, my brother. To all of a sudden be dumped at school for a couple of hours with all these strange kids and people I only see for a couple of hours and then are gone, made school very unreal for me. I did not participate. In kindergarten, I remember the toys and swings. I played pretty much by myself. I had a great deal of trouble remembering people's names. I still have that trouble. It's embarrassing to know someone, and you can't bring up their name. All the kids, their names didn't stick in my mind. How could I interact with this person when I didn't know his name? I just kept my mouth shut and did my own thing. I

remember I was sick a great deal. I had had tonsils and adenoids, so I was sick with colds a great deal of the time. That would reinforce home with my mother, and getting support from her reinforced home as my central reality, and everything else was meaningless, and unreal world."

After Rod's first year in kindergarten, Rod's mother was called in for a conference. The teacher recommended summer school because Rod didn't know the alphabet and couldn't hold a pencil correctly. He went to summer school, and his mother worked with him. His grandmother was a teacher, and she worked with him also. By fall, he could write his name, he knew his numbers, and he could print his alphabet, but the principal said that he didn't know how to use a pencil and that he would face failure if he didn't repeat kindergarten. Rod's mother said, as she told the story in the 1959 interview, "That was a bunch of malarkey. I had no trouble getting him to hold a pencil. I told my mother and she was mad. I don't think Rod has difficulties, except he's shy." The school psychologist had observed the kindergarten, and Rod's mother commented that Rod would have been so frightened under those circumstances that he wouldn't have been able to do anything. In fact, the school psychologist had given Rod an IQ test before summer school, and he had scored 68, which placed him in the mildly retarded range. When his mother refused to have Rod repeat kindergarten and be in the same class as his brother, the principal told her about a special class in another school. She told him that would be fine for Rod. With Rod's speech problem, she felt the special training class would be the best place for him. There were only eight children in the class, and his mother thought the teacher was marvelous.

At six, Rod was small for his age, and because of his frequent infections, his mother took him to the doctor. The doctor said that Rod's development was less than a six-year-old's and that Rod was anemic. After Rod had his tonsils and adenoids removed his health improved.

Rod was bussed to the special class. He was frightened of the new situation, but he does not recall thinking that the work was too easy or the other children were very different from himself. He says, "I remember we would do homework, cut pictures from the Sears catalogue. I remember having to write my alphabet twenty times and my brothers phonics book. I liked phonics. One event in the special class that stands out was when the teacher brought a picture of a little boy in a baseball cap and a bat. My little sister was just born, and I was excited about it. I would feed her her bottle, and I really loved my sister. I'd play with my brother. The boy in the baseball cap was looking angry and jealous, and the mother and father were standing by the crib. The boy is feeling left out. The teacher showed the picture and said, 'Rod, you just had a little sister. Don't you feel like this? Jealous, angry?' I wasn't usually called on in class to answer anyway. This type of question floored me. 'No, I love my sister.' 'Don't you feel upset?' This went on for five minutes. I felt this shock that I'm supposed to hate my sister or feel bad that I would have to play by myself. I felt guilty that I wasn't responding the way she wanted me to. The teacher was getting frustrated. I could tell by her tone of voice. I felt horribly bad that I wasn't acting the way I was supposed to act towards the babay. I loved my sister; I grew to hate her later on for other reasons (laughs), but at the time, my mother let me play

with her and feed her; I didn't feel left out. I had my brother to play with. He was a few months younger than I. I felt there was something inside me that certain things were right and certain things were wrong. I should love my sister and everybody else. Why should I be jealous or angry? I don't think the teacher meant any harm, but I remember the horror of the question. Teachers want certain answers and if you want to get along in school, whether you believe it or not, you do the 'right' thing. I have a natural desire to please people and be friendly and courteous. A teacher shouldn't inculcate those things. The teacher thought that the normal pattern was that you weren't going to get as much attention with a new baby in the house, and you will be jealous. I didn't fit into that pattern. That's why I got into that class. I didn't fit into the right pattern. 'There's something wrong with Rod.' I didn't open up and say some of the things I was thinking about. Maybe no one asked me what I was thinking about."

Rod's mother remembers the class also. She remembers trying to explain the concept "more" to Rod and not being able to get him to generalize the idea to the problem in the workbook that she had bought him. She needed to go wash clothes, so she finally told him to go watch TV. Rod's grandmother helped him learn to write, but Rod's mother was concerned that he not get too far ahead of his class because she didn't want him to get bored. She thought that Rod knew that he was ahead of his class. She said that Rod's problems were not the same as the others in the class. She felt Rod would improve if her husband did not demand perfection. She felt she neglected Rod for the other kids, and that he had to grow up too fast, that there was too much pressure on him to be perfect. In 1959, when she was asked if she thought that Rod would grow out of his handicap, his mother replied "Oh, he's done worlds better." She said that Rod would eventually have to go into a regular class. There was one little girl that he liked, and he was beginning to imitate her handicap.

Rod's father would not let his wife mention that Rod was going to a special school. He didn't want anyone to know. Rod's mother thought that the problem should be admitted and dealt with, not hidden. She thought that children's problems were created by adults.

Although Rod had a speech problem, he received no special speech training while he was in the special training class. When his mother felt it was time for Rod to return to the regular classroom, the school authorities would not transfer him. Rod's mother had to persuade her husband to move to another school district in order to get Rod out of the special training class.

Rod recalls, "When mom got very upset about that class, she persuaded my father to move, when I was about eight or nine. When I went to the new school, I went to speech class. I had difficulties with my s's, my r's, my th's, my d's, the works. Classes were fine because I was called out of class and got to play these interesting games, didn't have to do my math homework. I had trouble with math. In multiplication, when you have to slide everything over, I wanted everything neat and orderly. It took weeks; the teacher would sit with me. I still have to add on my fingers every now and then. Higher math I can handle. I would grudingly do the

work I was expected [to do] in school, and then when I'd get home, I'd do my own educative work with my own interests. So much so that while I was doing barely passing grades in sixth grade, I had in fifth grade taught myself, during the summer, binary math. A lot of the things just before new math had hit the area, I was already playing around on the side with some of the ideas and concepts that I was familiar with when the new math hit, and I was ready for it. I also had read this thing on the slide rule, and I taught myself how to use a slide rule in the sixth grade which I would use at home to play around with the homework problems just for my own amusement."

Rod continues telling about how his interests were not the same as his school work, "I got interested in reading when I saw a brochure in Sunday school class on the California missions. This was one of those events in my life that turned things around. Up until now, we learned about George Washington who was on the other side of the country. Those were like fairy tales. This was right here. I got all the books at the library on California missions, then dinosaurs and astronomy. At the new grammar school, I was the expert on astronomy. I was very fascinated with the Griffith Park Observatory, looking through the telescopes, seeing the moon in its crescent phases through the scope, the planetarium show."

"One of the most important events in my life occurred at age ten or eleven, in the early sixties during the Cuban crisis. I liked science fiction movies. I shared a room with my brother. I wondered what it would be like to die. I envisioned everybody's death. What if there's no God? Imagined the state of affairs. This was like meditation. This incredible wave of loneliness came over me. I then imagined myself dying. My body became smaller and colder. Strip away the body and leave my naked 'I'. I don't think I imagined myself as dead, but was going toward nonexistence. Although that would be impossible because I was thinking. Whether there was meaning or no meaning, that would be the worst thing. To be born, live, and have children, and have, at the moment, to know there was no purpose. I remember sobbing or whimpering over this angst. I committed myself to solve this problem, to find an answer. Do I have immortality? Why do I have to die? Why am I learning this stuff at school when it doesn't address the problem? It gave life more meaning to find the answer. This was an early age to think about such things, and it affected my life. I'd see the others playing ball, and I'd think how can they be doing that when they all might be dead the next day? I'm religious. Whatever my life, if it gives grace to God, then that's fine. I felt I should act in such a way to help others to find the answer. This contributed to my introspective nature. It increased my sense of justice. You don't mistreat people or cheat on tests. I was interested in astronomy; it was the origin of the universe, dinosaurs, the origin of life, mathematics, algebra, geometry, selfevident truths. There is God, and there is hope, but I had to find this out. I would read about world religion. Maybe God needed me to be an introvert so the extroverts could be. This event at ten or eleven gave me direction."

As Rod grew up, his father drank more heavily and was still abusive to the family. Rod played chess with his father and talked with him long into the night to placate him.

"The next big thing happened on September 17, 1967, in junior high school," Rod continued his life's story. "I cut a notice of a meeting of a literary society devoted to J.R. Tolkien out of the news paper." Rod went to the meeting and suddenly found there were people to talk to on the philosophical topics that he had been pondering by himself. He met a girl at the meeting and they began arguing about religion. To settle their conflict, they began reading the Bible. They spent hours on the telephone reading to each other and discussing what they had read.

Rod told about the discussions with his girlfriend, Jackie, "I remember reading Revelation in the Bible, and I would confuse the 'p' and 'b' in the words lamp and lamb. I would read about Judaism but came to the conclusion that Christianity made the most sense. My girlfriend, Jackie, was blasting Christianity, and I told her she didn't know anything about it. My father was a neo-Nazi and didn't like the idea of my Jewish friend. Jackie and I decided to read the Bible together. We would read to each other on the phone. I was visiting different churches and studying astrology and the occult. That was a dead end, because it's a power trip. About this time I became an Episcopalian. I was drawn by the liturgy. I began reading Aquinas and got interested in Catholicism. When I became Catholic, I went to confession, and it was very therapeutic. All these years people told me their problems. No one heard my problems."

When Rod graduated from high school, he moved in with friends from his literary group. His mother got the courage to leave his father and Rod's feeling that Rod was the glue holding the family together was confirmed.

Rod went to a junior college and a local university, majoring in philosophy. He went on to get his masters degree in library science. His first job was in a book store where he became manager. He finally got a job as a librarian. He tells how he got the job, "Before I worked as a librarian, I was a manager at a book store. I applied to [a mental institution] and I thought I wouldn't get it. They asked questions like, 'What would you do if someone hit you?' I said I'd be preventative. In the bookstore, if you thought someone would shoplift, you'd go up to them and say, 'Hello, can I help you?' The next day, after I went to confession, I got the job. Then I worried that I would have to deal with the criminally insane. Now I find that they are people. I'm finding books for them to read, cracking jokes with them. One man was having delusions and murdered his wife. I gave him a book to help him grieve for his wife. What he did was horrible, but I find myself liking him. I have become effective because I have patience. I'm happy about my job. The course I set at ten or eleven is going full steam ahead. I'm putting it together and am helping others to put it together. I can do as I wish as a librarian there. I've been able to reorganize the whole library. I've been creating it in my own image. It's not my library, it's their [the patients'] library. I'm there for the patients' service. I've tried to update the whole collection. We take sixty magazines."

Rod married Jackie and they have two children. He worries about his son, whose personality is similar to his own. Rod wants to be sure that his son does well in school. He doesn't want his son to be wrongly evaluated as he had been, since dyslexia runs in his family. Rod's life

history demonstrates the accuracy of his mother's comments in her interview in 1959. His mother was convinced that Rod was not retarded. She said, "I think Rod will do real good when he buckles down. He'll have to go to college. I don't think he'll have any problem if he wants to be anything, a doctor or a teacher. I don't think he'll have a bit of trouble." Recently, Rod's IQ was re-evaluated and he scored in the very superior range. He was anxious during the testing and eager to achieve the best possible score. He was visibly pleased with the results.

Rod Talks About His Being Wrongly Evaluated

Rod did not know that he had been labeled retarded until this research study began. He was asked how he felt when he was told he had been labeled retarded. He replied, and added his opinion of the labeling process.

"At age thirty-two, when my mother first told me, I thought, I tied my shoelaces, well, all right, go call the researcher; I'll have an interview with her and show her I can tie my shoelaces, a bit of bravado. I'll do a demonstration and show my stuff, but my inner thought was--I knew that I had many problems, my intense shyness, my inability to really deal totally with other people on a social basis, working on these problems and mental experiences that nobody else was thinking about, or at least to my knowledge nobody was thinking."

"I did one thing, I remember, as we'd been researching this matter, looking at scores of the reading level I was on for the fifth or sixth grade. In the Los Angeles city schools, I was on reading level, fourth or fifth grade. The teacher had written that I was reading eighth grade level material on my own. So what is the reality of what I was doing and experiencing in regards to outside observation, people observing the children, making their particular notes as to what is it we're looking for when we're saying this person is mentally deficient or this person is very, very gifted. My math grades in grammar school were probably mediocre, but I was fiddling around learning binary, a little bit of algebra, and slide rule at home, so what was that? I think many students can start out very, very slow and very, very quickly, depending on whatever the individual internal makeup. I can't draw, except little stick figures, though I can write handsome letters and compose a fine paragraph whenever I want to. But should the criteria of mental ability be on can the person hold a pencil? There's something about people that you just can't absolutely predict, some type of inner quirk, where you will do things normally, but they do something different and it's just not fitting in the mold and you either force them into it or you just label them and dismiss them and go on with churning out whatever society wants in its educational theories of school. I think that it's important to realize that people cannot always be absolutely pigeon-holed. I think that you can to an extent make predictions or make personality types, but people aren't always true to type. There's always something that breaks through and throws the thing off. According to the scores, I'm either mentally deficient or I'm extremely bright. What's the truth, what's being analyzed in this? I don't think I'm mentally retarded, I'm not very, very bright; I just think I'm very well read and can pass an IQ test with flying colors these days,

so what does it mean? I can read a book, write a nice paper, and that's maybe intelligence for society. Put me on a desert island; I'd probably die in three days, while a savage who doesn't know how to multiply or add knows how to cook and hunt and that's the intelligence skills you need to survive on an island, so in that case, on an island, I'm mentally retarded and this ignorant savage is brilliant. I think it's important to remember what it is we're measuring for. What is the purpose of this thing? And keep in mind that there are different contexts of things in the construction of society or different parts of society."